Swimming in the Stream:

Being a Health Professional and Doing Chronic Conditions Healthcare

Anna Spinaze

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Dedication

for my sisters under the skin, Dr Jae Spinaze and Dr Annette Hackett

former and current healthcare professionals who inspire and motivate me

in wonder at how they do long-term conditions work - at home and professionally

and to other academics, on whose shoulders I stand daily in an attempt to see.

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.

T. S. Eliot, Four Quartets

Declaration of Authorship

I, Anna Catherine Spinaze, am the author of the thesis titled *Swimming in the Stream: Being a Health Professional and Doing Chronic Conditions Healthcare*, submitted for the degree of Doctor of Philosophy (Medicine). I declare that the material is original, and to the best of my knowledge and belief, contains no material previously published or written by another person, except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright. This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution.

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First: research participants. You allowed me access to your work, and in some cases, to your personal lives as well. You all taught me a lot of life lessons, as well as chronic conditions healthcare lessons. I hope this thesis at least partially conveys some of your joys and some of your concerns.

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~ it takes a village to complete a PhD ~

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Declaration of Environmental Impact

This thesis has been undertaken with constant attention to environmental harm minimisation. Work was largely undertaken in a partially solar-powered home office, minimally heated using appropriately stored and manipulated firewood and partially solar-generated electricity. Office appliances (computer, screens, and printer) were switched off during downtime. University office space was shared, with existing resources utilised rather than replicated.

I came into the candidature with my own laptop, and refused a new one (offered on entry) until my own became unusable. The laptop I was then issued was used from 2008 to 2015 (and, touch wood, is still going strong), with two complete software upgrades/reinstallations (and two further refusals of new laptops during candidature). Printing was been minimised (screen friendly reading options pursued wherever possible). All printing has been double-sided and used 100% recycled paper where possible; through UniPrint, existing university printers (UDRH and Sociology) or at home on a reclaimed ex-institutional printer using recycled cartridges (kindly sourced through UTas Dept of Sociology and Social Work). Paper waste was recycled through university white paper recycling programs wherever possible. I advocated periodically as necessary for 'green office supplies' purchases within the various departments who supported me.

Fieldwork was undertaken using a small fuel efficient car, coordinating schedules to minimise driving, and choosing minimalist accommodation options (including camping). All interviews were recorded using borrowed equipment (digital voice recorder) rather than purchasing my own, with recyclable batteries charged from partially solar powered mains power. I had two mobile phones during the duration of the candidature, the first a hand-me-down and the other an unexpected present (which I hope to last ten years! Three years so far). I minimised conference travel, but where required to fly, chose flight equalisation schemes (so-called carbon neutral travel options).

When one tugs at a single thing in nature, he finds it attached to the rest of the world.

John Muir

Signed by the candidate, Anna Spinaze

July 2015

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List of Acronyms and Definitions

AIHW	Australian Institute of Health and Welfare
ATSI	Aboriginal and Torres Strait Islander peoples (Aust)
CARPA	Central Australian Rural Practitioners Association
CCM	Chronic Care Model, as developed by Wagner et al. See Section 2.4.2.
CCSM	chronic conditions self-management. See Section 2.4.3.
CDSM	chronic disease self-management. See Section 2.2.
CDMP	Chronic Disease Management Plan (Aust). See Section 2.5.1.
CHN	community health nurse (Tasmanian term for an RN who provides nursing services at home, also known as district nurse or visiting nurse [Aust])
COPD	chronic obstructive pulmonary disease
CRANA	Council of Remote Area Nurses of Australia
DE	diabetes educator (registered health professional with advanced qualification in diabetes support, most usually with nursing background)
DHHS	Department of Health and Human Services, Tasmanian (state) Government
DoH	Department of Health, Australian (federal) Government
DoN	director of nursing (nursing ward manager /community health services manager)
EN	enrolled nurse
EPC	Enhanced Primary Care package (Aust) - Medicare item enabling subsidized allied health visits
GP	general practitioner
GPMP	General Practitioner Management Plan (Aust). See Section 2.5.1.
GTMOOL	Get The Most Out Of Life (also known as the Stanford model): self-management patient education program
HACC	Home And Community Care package (Aust). See Section 2.5.1.
HP	health or healthcare professional (any allied health, nursing, medical or para-medical health worker, trained through a university degree qualification and registered through the Australian Health Practitioner Regulation Agency)
NHS	National Health Service (UK)
NP	nurse practitioner (registered nurse with a Masters in a specialist clinical area)
NRHA	National Rural Health Alliance (Aust)
NUM	nurse unit manager (nursing ward manager /community health services manager)
MAHS	More Allied Health Services (Aust). See Section 2.5.1.
MBS	Medicare Benefits Schedule. See Section 2.5.1.
MS	multiple sclerosis

MUPS	Medically Unexplained Physical Symptoms (an acronym used for difficult to diagnose physical symptoms where no particular condition or syndrome is yet discernible)
OT	occupational therapist
PIP	Practice Incentive Payments (Aust). See Section 2.5.1.
PN	practice nurse (general practice nursing)
RN	registered nurse
RAN	remote area nurse
SARRAH	Services for Australian Rural and Remote Allied Health
SIP	Service Incentive Payments (Aust). See Section 2.5.1.
TCA	Team Care Arrangements (Aust). See Section 2.5.1.
VTI	video-triggered interview (video ethnographic method formulated for this research, similar to Raingruber, Carroll, Iedema and others. See also Section 4.4.1)
WHO	World Health Organization

Abstract

This thesis is about chronic conditions healthcare. In a world of increasing chronic conditions prevalence, chronic conditions healthcare exists in experimental as well as more formalised forms. Drawing on observations, interviews and video-triggered interviews; this thesis documents present-day chronic conditions healthcare in regional Australia. It provides thick description of the experience of chronic conditions healthcare in response to the question: what is the lived experience of doing healthcare work with people with chronic conditions?

The key finding is that chronic conditions healthcare is a distinct but largely implicit part of healthcare work. Participants are beginning to formulate their own definitions of chronic conditions healthcare, and creative ways of engaging with the tasks of such work. Findings explore clinicians' definitions (individualistic, sometimes multiple, and generally indirect); tactics and techniques used; and external factors which shape chronic conditions healthcare.

At present, healthcare workers are 'swimming in the stream' of chronic conditions healthcare, staying afloat though immersed in a constant flow of clinical need. Incremental healthcare change is presently created through bottom-up "appropriating, resisting, and hybridising" of existing professional care-giving practices (Dombroski 2012, p. v), more than through top-down reorienting of healthcare systems away from acute and towards chronic conditions as the dominant priority. Characteristic dimensions construct health professionals' experience of chronic conditions healthcare: temporality, ambiguity, complexity, and contingency. Such dimensions constitute chronic conditions healthcare as qualitatively and pragmatically different to other kinds of healthcare work.

This research highlights three aspects of chronic conditions healthcare. First, not all healthcare change comes from above, through institutionalised change management. Considerable change comes from below, from the grassroots of the actual people doing healthcare. Second, the acute care focus of the healthcare system presents considerable challenges for chronic conditions healthcare. Third, chronic conditions healthcare remains marginalised in culture of healthcare. I argue that naming and explicitly describing chronic conditions healthcare is an important first step in improving chronic conditions healthcare. Chronic conditions healthcare is an entity which warrants exploration and establishment as a healthcare sub-discipline in its own right.

Foreword

I undertook this PhD as part of a broader Tasmanian government Department of Health and Human Services and University of Tasmania 'Partners in Health' program (2005), which initially sought candidates wanting to explore the relationship between community strength and health and wellbeing in rural and remote Tasmania. As a rural resident throughout childhood, and later as an adult, I am aware of the importance of health professionals as role models and community volunteers – their social as well as their healthcare roles.

Prior to an Honours year in sociology I was a medical student at the University of Newcastle (1999-2001). My peers and I were beneficiaries of a number of specific government programs aimed at attracting students to rural and remote healthcare. I received a scholarship for students from rural backgrounds, had a rural GP mentor, attended rural health conferences and made many friends and contacts within the multidisciplinary rural student and professional networks. I also had a practical introduction to medical feminism in action, as national portfolio holder (Gender Issues) for the National Rural Health Student Network. As a rural-focused medical student, I was enabled to participate in national and international rural workforce research projects, initially as an interviewee, and later as a steering group member, research assistant and project coordinator. I had also worked as a disability carer, and later as a research assistant on an ARC retirement intentions project. My Honours thesis explored why rural and remote health professionals choose to live in rural and remote areas (Spinaze 2003, 2008, 2009a). The findings of that research, namely that spatial and social connectedness were equally important in determining work and life location choices, highlighted geographical as well as social factors which interacted with both structure and agency for rural health professionals.

My adult rural residencies and academic biases (whilst unexpected to the childhood me) are a statistically probable outcome of my childhood in rural Queensland. At seventeen I could not wait to leave my country town, and initially pursued a career in classical music performance completely incompatible with rural residency. After later changing career paths, I found myself unsatisfied with metropolitan or even major regional life. As an aspiring rural GP doing medical studies in Newcastle, I missed my adopted state of Tasmania desperately, and withdrew to live for the first time as a rural adult, with friends near Cygnet. I was ready for time outside even the regional city of Hobart, and found myself nourished whilst surprised by a different rural culture and climate; very distinct from my childhood understanding of rural as 'hot, sweaty, sport-monopolised, and a cultural desert'. As an active member of different Tasmanian rural

communities over a number of years, I observed thriving arts scenes and cutting edge community healthcare. During Honours and PhD candidature, I undertook research in communities in which I had lived, as well as in other rural, regional and remote locations; and for some PhD fieldwork was accompanied by my partner and baby, or by my father and toddler. I thus had experiences both of being a 'stranger' and a 'local'; as outsider "tabula rasa, safe, neutral, naïve and objective, someone to talk to who would go away after a discrete period" – and as a local with "both improved and more difficult access, more complete though perhaps more subjective knowledge and understanding of the history of the community, and the bias of being a resident" (Spinaze 2003, p. 17). As a 'mainland refugee' rather than Tasmanian born and bred, in some respects I am always only a partial Tasmanian, and moving closer to Hobart during the last stages of writing-up further removed me from one particular kind of rurality. Nevertheless, contacts made and jargon learned, during disability support work and medical school, give me entrée to worlds of healthcare professionals which other social researchers may not have. My rural childhood, Honours fieldwork, sharing of child raising, and rural residency during research also give me access to daily life-worlds of healthcare professionals beyond their clinical settings.

I thus commenced this PhD very aware of (a) the political nature of funding for rural and remote healthcare (2) the physical and emotional nature of different kinds of healthcare work, and (3) some of the social and sociological forces at play, within rural communities, ageing Australian populations and ageing Australian healthcare workforces. I am neither a clinician nor a true sociologist, having partial undergraduate degrees in both. As a social researcher of healthcare without lived professional experience of a particular discipline, I nevertheless retain 'partial insider' understanding of some healthcare work. As a social researcher, I find intellectual sustenance within interpretive sociology, cultural geography, and rural health. I am thus positioned to explore different disciplinary contexts with both less understanding, but also hopefully less bias than particular disciplinary qualifications and affiliations might give. I consider both myself and this thesis primarily advocates for rural and remote health in the broadest sense: where the phrase 'rural health' functions as a proxy indicator, a social justice flagship for multiple healthcare system (and community) equity issues.

PART ONE: SCOPING THE TERRITORY

1 Chronic Conditions Healthcare as an Area for Study

1.1 Introduction

Chronic conditions healthcare[1] is at the heart of most clinician-patient encounters today. Seventy percent of Australian GP consultations are chronic conditions related (Britt et al. 2008), more than eighty percent of Australian healthcare spending is chronic conditions related (Australian Institute of Health and Welfare 2008), and the World Health Organization "acknowledges that the largest global healthcare challenge of this century is the prevention of chronic diseases" (Johnson & Chang 2008, p. 1). Chronic conditions, those "characterised by

- complex causality
- multiple risk factors
- long latency periods
- a prolonged course of illness
- functional impairment or disability" (Australian Institute of Health and Welfare 2015a)

appear to be one of the dominant healthcare problems of our time. Yet chronic conditions healthcare is not yet conceptualised as a specific set of skills and understandings; and the

[1] I define 'chronic conditions healthcare' as the professional healthcare of people with chronic conditions.

I use 'chronic conditions' rather than 'longterm conditions', as a term more familiar to the Australian healthcare professionals who are the research focus. I acknowledge the confusion created by lay interpretations of the word 'chronic'. However, in this thesis (which may be read by lay, academic and clinical readers), an understanding of 'chronic conditions' is intended to be simply longterm physical and mental conditions, illnesses and disabilities. Chronic conditions include chronic illnesses, chronic diseases, non-communicable diseases, and ambulatory care sensitive conditions (Manitoba Centre for Health Policy 2010). Many chronic conditions are not 'serious', 'life threatening' or 'life limiting' (terminal). However other chronic conditions have potential for acute episodes, increased functional impairment or life threatening episodes.

I deliberately use the word 'healthcare' rather than 'care', to signify the work of paid professionals rather than the work of people with chronic conditions themselves (as well as the work of family members and friends who undertake support for activities of daily living). The term 'healthcare' may also imply the tertiary training common to registered healthcare professionals, and thus distinguishes this kind of work from that of paid but not tertiary-qualified support workers. Using 'healthcare' also avoids the term 'long-term care', which (in American and increasingly Australian parlance) indicates institutional care of frail aged or critically disabled.

dimensions of chronic conditions healthcare from the perspectives of clinicians have not been explored.

Chronic conditions healthcare is an integral part of daily clinical practice, and, even more than the established sub-disciplines of healthcare, a daily part of primary care and primary health care[2] workloads. However, some sub-disciplines of healthcare - like palliative care, Aboriginal healthcare, aged care, emergency medicine and others - have profiles within healthcare systems and healthcare planning in a way which chronic conditions healthcare does not.

This thesis aims to make visible and examine the nature of chronic conditions healthcare; conceptualized for the purposes of research, planning and policy as a distinct, separate entity. In addition, the thesis demonstrates that the changing morbidity profiles of populations, and the changing social profiles of health workers, are radically affecting both *who* practices, and *how* people practice, in particular as clinicians in rural areas. The pressures on those who do the increasing amounts of chronic conditions clinical work have, to date, largely been invisible.

This thesis will demonstrate that primary healthcare workers are presently 'swimming in the stream', to appropriate an old public health metaphor. Rather than busying themselves downstream fishing out people with chronic conditions, or taking the direct public health action of going upstream and trying to stop people falling in, present workloads necessitate 'staying afloat' whilst immersed in a constant flow of clinical need. When it comes to chronic conditions healthcare, health professionals are working reactively, making it up as they go along. This is despite the bulk of daily healthcare work being with people with chronic conditions. There is a need to understand the social dimensions of chronic conditions healthcare, because our clinicians presently do a lot of it, and will need to do more. There is a need to understand the social context of chronic conditions healthcare, because the distribution and stylistic approaches of healthcare workers are only partially meeting chronic conditions demand. A deeper understanding of what chronic conditions healthcare is, and how it takes place in particular locations, will help us determine policies which maximise the functionality of people already diagnosed, and diminish the likelihood of onset. Fundamentally, healthcare workers need to work with chronic conditions better.

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[2] 'Primary care' in this thesis will refer to the principle (often initial) place of treatment (in Australia generally a general practitioner, community health centre and/or hospital emergency department). 'Primary health care' incorporates this, but also refers to the broader philosophical intent of service delivery, where equitable resource distribution, community involvement, and preventative healthcare were intended by the WHO's Alma Ata Declaration (1978). In Australia, "primary health care is [largely] concerned with treatment, cure and care of people with illness, [alongside] illness prevention and health promotion" (Baum 2008, p. 589).

I argue that the personal, social and historical factors affecting chronic conditions work need examination. This thesis thus explores the experience of being a healthcare professional and working with people with chronic conditions in three parts. Part One (Scoping the Territory) outlines the problem and topic of research, conceptual frameworks, research context, and research methodology. Part Two (Findings and Analysis) consists of three chapters which combine results and analysis, examining participant definitions of chronic conditions healthcare, tactics and techniques of chronic conditions healthcare, and external factors which shape the doing of chronic conditions healthcare. Part Three (Discussing and Concluding the Research) has three chapters. The first discusses overarching commonalities (ambiguity, contingency, complexity and temporality) as characteristics of chronic conditions healthcare. The second outlines some implications of the findings, whilst the concluding chapter consolidates the chronic conditions healthcare snapshot and theorisation presented.

1.2 Why this research?

1.2.1 Chronic conditions as the dominant worldwide healthcare problem

In 2012, the World Health Organization considered chronic diseases "by far the leading cause of mortality in the world",

> … representing 63% of all deaths. Out of the 36 million people who died from chronic disease in 2008, nine million were under 60 and ninety per cent of these premature deaths occurred in low- and middle-income countries (World Health Organization 2012).

American statistics are similarly dire. "Chronic disease is the nation's greatest health care problem" is a statement which sits alongside the projection that "roughly 50% of the [American] population, roughly 157 million, will have at least one chronic condition by 2020", and an observation that current American medical care costs for treating individuals with chronic conditions sit at 83% of current expenditure (Lubkin & Larsen 2006, p. 3). Worldwide (including developing countries), the 35 million projected chronic conditions deaths in 2005 were 80% of the total deaths in low- and middle-income countries (Baum 2008, p. 235), and "double the total number of deaths from all infectious diseases (including HIV/AIDS, tuberculosis and malaria), maternal and perinatal conditions and nutritional deficiencies combined"(WHO 2005, cited Baum 2008, p. 243).

With "the greatest proportion of chronic disorders affecting the older population" (Lubkin & Larsen 2006, p. 8), the demographic shift (population ageing) common to industrialised countries

is of concern: comorbidity (multiple rather than single conditions) is also common in chronic conditions occurrence, and rises with ageing (Lubkin & Larsen 2006, p. 8). In addition, "having a physical illness is one of the strongest risk factors for depression", and comorbid depression prevalence is "markedly and consistently higher" in people with heart disease, stroke, diabetes mellitus, asthma, cancer, arthritis and osteoporosis than in the general population (Clarke & Currie 2009, p. S55). Alongside comorbidities, "longterm and iatrogenic effects of some [chronic condition] treatment methods may constitute chronic conditions in their own right" (Lubkin & Larsen 2006, p. 6). For example, haemodialysis is imperative in chronic kidney disease, but has distinct side-effects and specific risk factors for additional diseases such as infections. Such separate risk factors of treatment are additional to the original chronic disease risk factors and burden.

In Australia, "chronic illness[3] and disability are a hidden economic burden" (Parry 2012, see also Jan, Essue & Leeder 2012). Australia continues the developed world pattern, with "77% of the population hav[ing] at least one chronic condition, and … chronic diseases (including cancers) account[ing] for more than 80% of the burden of disease and injury" (Australian Institute of Health & Welfare 2006, cited Swerissen & Taylor 2008, p. 76). Considerable healthcare expenditure is made on chronic conditions nationwide: with "the major chronic diseases account[ing] for about $30 billion (60%) of all allocated health care expenditure" (Swerissen & Taylor 2008, p. 76), and "over one-fifth ($11 billion) of all health system expenditure in 2001 taken up by the 12 chronic diseases highlighted [oral health, coronary heart disease, osteoarthritis, depression, cerebrovascular disease, diabetes, asthma, kidney disease, chronic obstructive pulmonary disease, rheumatoid arthritis, colorectal cancer, osteoporosis, lung cancer" (Australian Institute of Health and Welfare 2006, p. 44).

Holman suggests two issues are "intrinsic to the provision of health care": "the emergence of chronic disease as the dominant healthcare problem" and "the changed role of the patient" (Holman, H 2005). However, I also argue that there is a third issue intrinsic to the chronic conditions healthcare context: the changing demographics and identities of healthcare professionals. To understand chronic conditions healthcare, there is a need to understand the lifeworlds of the clinicians who are doing it. In addition, the kinds of healthcare professionals who do chronic conditions healthcare construct both how such work is done, and how much of

[3] The personal experience of one or more longterm diseases, syndromes, dysfunctions or conditions and their consequences; over time (based on a definition by Holman, HR 1993, p. 31).

it is done. In Part 1.2.2, I introduce demographics which affect the makeup of the healthcare workforce[4], and consequently who it is that may be doing chronic conditions healthcare.

1.2.2 Changing health worker demographics

The demographic profiles of health professionals are changing, paralleling the ageing of the general populations. General practice and nursing are particularly affected, with Schofield et al determining (from Australian Bureau of Statistics census data) that baby boomer GPs made up 59% of the rural GP workforce in 2001 (Schofield, D et al. 2006). The Tasmanian GP Census of 2010 notes that the Tasmanian GP workforce is one-third aged over 55, with less than 5% under thirty-five (less than half the national rate) (GP Tasmania 2010a). Schofield et al. also conclude that the rural nursing workforce is "slightly but significantly older" than the urban nursing workforce, and that rural GPs were retiring faster than urban GPs (Schofield, D et al. 2006, p. 3, see also Brookes et al. 2004). Allied health professionals in Australia are "young compared with the general health workforce" and "more mobile" than medical professionals (Dodd, Saggers & Wildy 2009), but equally in shortage, particularly in regional and remote areas (Gillham & Ristevski 2007).

As well as the ageing of healthcare workforces, work patterns within workforces are changing. The prioritisation of work-life balance, in comparison to previous work dominance, is striking. Shrestha and Joyce describe an increasing appreciation of work-life balance across all ages within the Australian GP workforce, but in particular by younger generation and female GPs (Shrestha & Joyce 2011). Allied health is similar, with Generation X, Y and Boomers all described as valuing work-life balance and flexibility of career work patterns at different times in their careers (Dodd, Saggers & Wildy 2009, p. 218). Shrestha and Joyce observe that "only half of the GP workforce reported good work-life balance" (Shrestha & Joyce 2011, p. 40), with "significantly more rural than city 'baby boomers' continu[ing] to work long hours" in the total medical cohort (Schofield, D et al. 2006, p. 1). Tolhurst and Stewart suggest many male medical students are aspiring to similar work-family-lifestyle balance expectations as female medical students (Tolhurst & Stewart 2004), whilst Piko notes "the most significant *decrease* in workforce participation between 2002 and 2007 occurred in male GPs under the age of 35 years." (Australian Institute of Health & Welfare 2009, cited Piko & Phillips 2010, emphasis added).

[4] In this thesis, 'health workforce' indicates those health professionals whose services are Medicare rebateable via referral from a GP (ie does not include most complementary or alternative health professionals such as osteopaths, massage therapists and chiropractors, despite their presence in and substantive contribution to chronic conditions work in rural areas (see Robinson, Anske & Chesters 2008). Further research is required to determine the distribution and contribution of complementary therapies to chronic conditions healthcare.

Nevertheless, this pattern is changing for younger professionals, with "rural 'generation X' GPs […] no more likely to work long hours than those in the city" (Schofield, D et al. 2006, p. 1). This indicates a shift in attitude across different generations of healthcare professionals, paralleled by public sector management interest in actively managing "work-life balance as a strategy to address labour supply problems" (Todd & Binns 2011, p. 1).

The rise of the 'boundaryless career' (that is, careers which take place across multiple employment settings (Arthur & Rousseau 2001), and even multiple countries (Buchan, JM, Naccarella & Brooks 2011) within medical as well as nursing and allied health workers (Schoo et al. 2005; Robinson, S, Murrells & Griffiths 2007; Dodd, Saggers & Wildy 2009; Piko & Phillips 2010), accentuates a growing sense that healthcare professionals will seek positions and work content which suits them and their families logistically and psychologically (Eley, Young & Shrapnel 2008). In other words, both male and female healthcare professionals are increasingly prioritising lifestyle and family responsibilities within their career trajectories (Piko & Phillips 2010). Rural practice appears to have become a lifestyle choice within a given period within a career (Spinaze 2003), rather than a lifetime commitment: a symbolic consumption reflective of chosen identity (see Rayner & Easthope 2001).

As demographics of health workforces change, so too do clinician work expectations, both in terms of hours available to work, and types of work preferred. The changing demographics and work-life balance preferences of the health workforce is discussed in Chapter Three and Chapter Seven; however, it is fair to say that these have considerable implications for the kinds and amounts of chronic conditions healthcare which will be pursued.

1.2.3 Cultural legacy affecting healthcare delivery

According to Johnson, "[f]unding for the delivery of healthcare has always focused on an acute care model" (Johnson & Chang 2008, p. 8). Thorne corroborates, noting twenty years ago that "chronic illness care is typically provided by professionals educated toward acute curative models, and in structures designed to provide emergency and highly technological services" (Thorne 1993, p. 9). With changing epidemiological profiles worldwide there is a shift in healthcare usage from predominantly infectious diseases and acute illness, towards longer-term conditions (chronic disease and disability) as the bulk of healthcare work (see World Health Organization 2005). However a concomitant shift in healthcare structures is yet to eventuate. This is prevalent in both developed and developing countries; however, my research focuses on developed parts of Australia.

Whilst there is a shift towards prioritisation of 'chronic', 'ambulatory', 'non-communicable' diseases and 'longterm conditions' in policy language and healthcare discourse, it appears that present healthcare arrangements are predicated upon a different (historical) set of needs, and a different (also historical) type of patient (see Holman, H 2005). Patients today may be asymptomatic, fully employed, a family caregiver and a local volunteer simultaneously; undertaking a very passive or very active role as healthcare consumer (May, C 2009; Dimond 2014). If, despite limitations in rural Australian data (Liaw & Kilpatrick 2008, p. 2), rural and regional Australia follows global and national patterns, it appears that chronic conditions patienthood in particular must generate a considerable portion of Australian rural primary, secondary and tertiary healthcare work[5]. Present-day approaches include clinical guidelines, care planning, and multidisciplinary team care; but it appears that such approaches are either not being delivered in rural and regional areas, or are being delivered ineffectively (as is discussed in Chapter Two). There is a sense of system-wide (possibly even a world-wide) inability to 'stem the flow'. The increased attention, policy discourse and public noise ('moral panic') around chronic conditions makes it important to examine the actuality.

There is some debate about whether the worldwide prevalence (rate per head of population) of chronic conditions is actually increasing, or whether "contemporary medical perceptions and explanatory frameworks … create the analytic space for their first emergence and continued existence" (Armstrong 2013, p. 11). The rise in what Beck and Giddens refer to as a 'risk society' mentality may be predisposing government action towards "greater monitoring and administrative supervision of workers, and a focus on managerial rather than therapeutic skills" (Sawyer et al. 2009). Where there is increasing 'noise' around chronic conditions, there is pressure on healthcare workers and healthcare systems to respond. The increased volume of both chronic conditions policy attention and biomedical research necessitates sociological examination; into the experiences of health professionals presently navigating chronic conditions healthcare.

Attention needs to be paid to how health professionals actually do chronic conditions healthcare, and what the experience of doing that kind of healthcare is like. This research explores individual health professional experiences, of the social and cultural conditions within which chronic conditions healthcare takes place, and which impact upon clinical management. Given the

[5] Primary care is "care the patient receives at first contact with the health care system, usually involving coordination of care and continuity over time". Secondary care is "treatment by specialists to whom a patient has been referred by primary care providers". Tertiary care involves "treatment given in a healthcare centre that includes highly trained specialists and often advanced technology" (Dorland 2000, p. 289).

growing bodies of chronic conditions medical research, chronic conditions policies, and chronic conditions patient perspectives, the voices of healthcare professionals need also to be documented.

1.3 Research Question

This research responds to May's call to "attend to the subjectivities and experiences of professionals, as well as those of sufferers and carers" (May, C 2005). Accordingly I ask and address the question:

What is it like, and what does it mean, to be a health professional
doing chronic conditions healthcare?

In exploring and thereby deepening understanding of what it is do chronic conditions healthcare, I propose a review of broader health work (contexts and status) and health workers, as well as of chronic conditions healthcare. We need to understand long-term healthcare as well as short-term, and understand those who do chronic conditions healthcare in primary, secondary and tertiary healthcare contexts. Exploration of such 'lived experience' and 'meanings' questions demands qualitative research focusing on meanings and interpretations. This will be discussed in detail in the methodology chapter (Chapter Four), however is introduced below.

1.4 Research Style

1.4.1 Qualitative

This research is firmly positioned in the qualitative research arena, inductive and interpretive; reflecting on the experience of healthcare professionals of doing chronic conditions healthcare. Qualitative research "typically seeks to generate empirical knowledge about human phenomena for which depth and contextual understanding would be useful, and for which measurement is inappropriate or premature" (Thorne 2008, p. 38). Such interpretive research is important, in that it "enables researchers to begin to engage with the complexities of meaning that are often emotionally, politically, and technically … very difficult." (Rice & Ezzy 1999, p. ix). Whilst healthcare research is often statistical (for example, epidemiological) or at the least mixed method, Baum suggests qualitative research can be useful to public health problems, in that such approaches emphasize "holistic understanding and the importance of context" and stress "not measurement but rather understanding" and "social, economic and political" aspects (Baum 1995).

Where there is extensive statistical knowledge, for example of rates of particular chronic conditions, we need more understanding of the associated meanings and interpretive practices. As discussed in Chapter Two, there is extensive knowledge of rates of occurrence and patient experiences of chronic conditions, however relatively limited understanding of parallel clinician experiences. In this research I provide a thick description of chronic conditions healthcare, describing a phenomenon in detail, in the hopes that understanding the work that clinicians are presently experiencing may provide insights into determining how they might do more (and better) long term conditions work. Within the healthcare system, clinician tactics as well as demographics are changing, and we need to understand them.

1.4.2 Rural focus

This thesis uses a rural lens, where the terms 'rural' and 'rurality' are used to indicate 'rural and regional' as distinct from 'remote' (rural-remote classifications and definitions are further discussed in Section 1.5.2). Farmer et al suggest that 'place' is the "omnipresent, but often unremarked variable" in rural health research (Farmer, Munoz & Threlkeld 2012, p. 188), and I suggest that place is often unremarked yet critical across *all* health research. Rural healthcare thus forms a critical case sample, "an information-rich exemplar [where] if that group is having problems, … we can be sure all the groups are having problems" (Patton 2002, p. 236). Studying the experience of chronic conditions healthcare in a critical case situation highlights issues which also occur in other cases, and lays ground for "logical generalizations … from the weight of evidence produced" (Patton 1990, p. 175).

A rural workforce focus also complements existing chronic illness[6] work, in particular Mary FitzGerald's 1995 doctoral thesis "The Experience of Chronic Illness in Rural Australia", which provides a comprehensive and rare account of the realities of living as a patient with chronic conditions in rural Australia. It is an interpretive phenomenology written by a nurse-researcher, and elucidates the combined difficulties of complex, often multiple chronic conditions and reduced medical options due to living at a distance from major centres. In building on patient chronic illness experience literature (the impact of which is discussed in Chapter Two), FitzGerald contributes a rural chronic illness patient voice. This thesis validates and extends such arguments, by adding the voices of rural Australian healthcare professionals to stand alongside

[6] 'Illness' is sometimes differentiated from 'disease' in health sociological literature, with 'illness' considered the experience (personal and social) of a disease, disorder, syndrome or condition (eg Kleinman 1998).

those of rural Australian patients. It thus strengthens the rural health justice narrative, which calls for equal health outcomes for all, irrespective of postcode.

A breakdown of Australian data suggests approximately one-third is spent on out-of-hospital medical services [mainly dental and GP], one-third for hospital services, and the remainder on pharmaceuticals, allied health services including community care, aged care homes and research (Australian Institute of Health and Welfare 2006, p. 41). If the regional, rural and remote population constitutes approximately a third of the Australian population (Liaw & Kilpatrick 2008, p. 1), and similar amounts are spent in rural as in metropolitan locations, then (based on Swerissen's figures above), rural chronic conditions healthcare expenditure may have been approximately $10 billion in 2001, and predicted to rise. It is also important to note that 'equal health outcomes' is not the same thing as equal access or treatment, but rather differential treatment according to needs, enabling equivalent mortality and morbidity statistics. In particular, more is generally spent per capita in remote areas, reflecting the high cost of services in isolated settings (see Wakerman & Lenthall 2002, p. 133). However, in the interests of consistency of use within this thesis of 'rural and regional' as distinct from 'remote', and to facilitate a clear argument, in the above estimation an equivalent spending estimate is used. Such figures warrant further investigation of the delivery of chronic conditions services in rural and urban Australia.

My research focuses on rural and regional healthcare professionals in order to use them as a thematic indicator for the function of the Australian healthcare system as a whole. In this way, rural and remote status (rurality) is considered another social determinant of health, alongside literacy, education, socio-economic status, employment and housing security ('the conditions in which people are born, grow, live, work and age" (World Health Organization 2013). Rural and regional issues also need to be distinguished from remote issues (despite some commonalities) (Wakerman & Humphreys 2008): a clear proportion of Australian rural health discourse is focused upon remote health issues, but this research is not part of that cohort. Remote healthcare has a separate set of issues, constraints, and contexts, and equally deserves direct attention. However rural-regional and remote healthcare share some issues in common: for example, the recruitment and retention of both rural and remote clinicians is generally considered more problematic than in metropolitan areas (Bourke & Sheridan 2008; Liaw & Kilpatrick 2008). Pressures on rural recruitment and retention are nevertheless mirrored in high-need urban areas, albeit with different manifestations in terms of access, availability and personal-professional boundaries.

Rural, remote and urban health differentials remain, with issues of "proximity, number and type of health services, the number of health professionals, and the ease of access to services" (particularly in the 'golden hour', "the first hour after the occurrence of a multi-system trauma." (Liaw & Kilpatrick 2008, p. 222). In the majority of remote areas of Australia, the cultural appropriateness of certain healthcare services is also generally considered to impact on health outcomes (Misan, Lesjak & Fragar 2008, p. 75). Heightened resource pressures within such areas, as well as epidemiological differences, contribute to making such areas higher need, which means that the experience of clinicians may be more pressured. Fewer clinicians per head of population may mean requirements for more service delivery within the same time (that is, shorter consults in order to achieve higher throughput), or alternatively more extended waiting lists where delivery cannot be compressed.

Experiences within high need areas are important because:

- they may help provide indicators of issues which need to addressed in order to facilitate easier recruitment and better retention within such areas (important in and of themselves); but also because
- such experiences may provide advance warnings of how individuals and systems function under pressure (important because they may provide clues to issues in other areas).

Bourke calls for evidence specific to rural health to be developed (rather than simply health research in rural areas) (Bourke 2007). However requirements for chronic conditions healthcare (quantity and quality) appear to be increasing throughout the healthcare system. While rural-specific evidence is particularly valuable to rural communities, it also provides clues for issues which may not be as clearly visible within more metropolitan communities but are equally present. Within the Australian healthcare context, rural healthcare is the canary in the mineshaft: an early warning indicator of pressures in the Australian healthcare system in general, as well as potential issues for chronic conditions healthcare worldwide.

In conducting rural and regional research, this study necessarily elicits rural and regional evidence. It is possible that the kinds of chronic conditions healthcare described and discussed in this thesis has characteristics specific to rural and regional chronic conditions healthcare; however the aim is to shine a light on issues which appear to be present across the Australian healthcare context. A separate remote or metropolitan focus might find different issues predominate; however, in the absence of equivalent research with metropolitan or remote participants, this research provides an initial window into some meanings and interpretations of chronic conditions healthcare. The findings are context-specific, which is not to deny their potential applicability in other contexts -

just as urban-based research cohorts provide indicators for potential rural solutions. The substantive themes within this research are likely to be common to clinicians doing chronic conditions healthcare across a range of geographic settings. This research leaves others to explore other settings, whilst documenting rural and regional manifestations of chronic conditions healthcare.

1.4.3 Multidisciplinary research approach and data

This research utilises a multi-disciplinary approach and data. While twenty-first century healthcare is inherently multi-disciplinary, one shortcoming of much healthcare research is its discipline-specific nature. It is important to recognise that different epistemologies exist within different healthcare disciplines (for example, medicine, physiotherapy and epidemiology as relatively positivist; nursing and social work as more constructivist, (see Bourke 2007). My research has relevance to those multiple paradigms, as exploratory work addressing the experiences of participants from many healthcare disciplines. This research intentionally explores the breadth of experiences of the multiple professions normally present in primary care (rural, regional and urban), in order to elucidate commonalities as well as distinctions, and create a more accurate picture of the whole of chronic conditions healthcare rather than separate aspects.

While findings specific to one profession are not always generalisable to other professions, this research describes similarities and differences in roles and identities apparent across professions. Further, one of the research funding bodies (DHHS) employs healthcare professionals from all disciplines (and more from nursing and allied health), and are necessarily interested in the views of nursing and allied health as well as medical employees. By describing similarities and differences, this research reinforces the commonalities as well as the distinctions between the diversity of health professions who are doing chronic conditions healthcare. This multi-disciplinary focus enables broader theorizing of chronic conditions healthcare, potentially enabling broader health system application.

1.4.4 Strengths-based approach, and Research Sub-Questions

In keeping with the anticipated findings from the research itself, the research write-up takes a strengths-based approach. The research was not initially designed to focus solely on strengths, or even to examine the situation with a strengths-based lens. As with most research, it initially fell into the "pervasive deficit discourse" (Comber & Kamler 2004, p. 293) of problem-based approaches. However, during fieldwork I was exposed to people working using strengths-based approaches, and attended training for strengths-based approaches as part of observation of

healthcare workers. Strengths-based approaches focus on determining assets (rather than problems) apparent in a given context, and building upon those, strengthening existing resources (see Kretzmann & McKnight 1993; Saleebey 1996; Lietz 2007; Hill, K 2008; Cederbaum & Klusaritz 2009). This research does not purport to be solely strengths-based, however I recognise the tendency of academic analyses as well as clinical healthcare to focus more on gaps than assets. The research question of this thesis was therefore refined with additional sub-questions to draw out strengths as well as deficits in the field:

What is it like, and what does it mean, to be a health professional doing chronic conditions healthcare?

- what are the issues for healthcare professionals in doing such work?
- what are the strengths of chronic conditions healthcare professionals?
- what are the strengths of chronic conditions healthcare itself?

1.5 Positioning the research: researcher and the research site

1.5.1 Positioning the research: the researcher

In keeping with interpretivist traditions, I acknowledge my own position in this research, and also the effects of the particular location on the research. While any research can have benefits, my own positioning as well as the positioning of the research inherently influences those benefits:

> Attempts to eliminate all biases are naive; therefore, the researcher must explicitly account for the influence of bias upon the research findings as much as possible. (Dreher 1994, cited by Thorne, Kirkham & MacDonald-Emes 1997, p. 175).

It is therefore important that I 'write myself into the thesis' (as per Schwarz 2006, p. 7), and also outline the type of place and time in which the research takes place, in order to demonstrate reflexive practice appropriate to qualitative methodology.

As discussed in the foreword, I have been a medical student, a sociological student, and a musician, resident in rural communities in Queensland and Tasmania. I do not quote material from my medical student experiences, nor from my rural community residency or advocacy work. Whilst this thesis is not at all auto-ethnographic, I take the viewpoint that all research is, to some extent, a document of self as well as external 'realities'. As with Atkins (Atkins 2010), this thesis interweaves personal and theoretical understandings of what chronic conditions healthcare in the present period is. My life experiences create influential groundwork, which to some extent determines research design and interpretation. My own experiences of the healthcare system, as patient, medical student, and social researcher, colour what I hope is a nevertheless holistic assessment of some social, cultural and personal assets which impact on health professionals'

capacity to engage in chronic conditions healthcare. As much as I may aspire and work towards the dominance of the voices of the healthcare professional participants in this thesis, my own thought processes and biases clearly take primacy within both the research journey and its product.

1.5.2 Positioning the research: Tasmania, Australia

In this section I describe the research site and cultural pre-conditions in Tasmania, Australia, as background to the present status of chronic conditions and chronic conditions healthcare.

Tasmania is a small island state off the south of the Australian mainland, and Australia's smallest state. With a cool temperate climate, only two areas of Tasmania are considered 'very remote' (Flinders Island and King Island) (Australian Institute of Health and Welfare 2004, p. 62); and the bulk of Tasmania fits into inner regional and rural designations (AIHW 2002, cited University Department of Rural Health [U.Tasmania] 2002). In addition to tourism, agriculture, forestry, mining and fishing contributing to its economy, Tasmania has "the highest proportion of artists *per capita* of any state or territory in Australia" (Department of Health and Human Services [Tasmania] 2012b), and considerable historical architecture (colonial through to present day).

Nearly one-third of Tasmania's land area is agricultural (Tasmanian Agricultural Producers 2011), and many of its rural areas could be considered 'latte rural' (Laurence et al. 2010). The majority of Tasmania is considered Outer Regional within the Australian Standard Geographic Classification index (Australian Institute of Health and Welfare 2015b), and the whole of Tasmania's residents (including the capital, Hobart) classified for some purposes as residing in rural and remote regions (Services for Australian Rural and Remote Allied Health [SARRAH], Lowe & O'Kane 2004)[7]. However, in contrast to other rural and remote parts of Australia, most of populated Tasmania is within reasonable driving time (less than three hours' drive one-way to a small to medium urban centre). The geography of Tasmania is thus a considerable drawcard to 'mainland' tourists, tree-changers and sea-changers. However, it is also sometimes considered isolated, a backwater, and joked about in ways similar to Newfoundland and Ireland (Alexander 2006). Equally it is fiercely a subject of "island patriotism" (Reynolds 2006).

Tasmania's total population is approximately half a million (Australian Bureau of Statistics 2013), and is dispersed and ageing (Larson 2006). The proportion of those aged 65 years and over,

[7] For a comprehensive overview of geographical classification systems as used in Australian rural health policy, see Wakerman and Humphreys, in Liaw and Kilpatrick's Textbook of Australian Rural Health (Liaw & Kilpatrick 2008).

compared with the total population, is expected to double by 2050 (Department of Health and Human Services [Tasmania] 2008, p. x). About half of Tasmania's population live in the south, with "28% in the north, and 22% in the north-west" (Department of Health and Human Services [Tasmania] 2008, p. x); totalling 98% inner regional or outer regional and 2% remote or very remote (Department of Health and Human Services [Tasmania] 2013b, p. 3). The stability and containment of Tasmanian populations generally increases with rurality (Orpin et al. 2005). Despite the presence of a state capital (Hobart), Tasmanian demographics as a whole demonstrate similar gender and ageing distribution patterns to those of rural and regional mainland Australia (Department of Health and Human Services [Tasmania] 2013b).

The health status of rural and remote people in Australia is generally considered poorer than metropolitan counterparts across a range of measures; including for long-term conditions (Misan, Lesjak & Fragar 2008, p. 80), and in particular for Australian indigenous peoples (Bourke, Coffin, et al. 2010). Tasmania's indigenous population is 3.5% (Department of Health and Human Services [Tasmania] 2008, p. x), which is more than Queensland or Western Australia and also more than Australia as a whole (2.3% indigenous, Department of Health and Human Services [Tasmania] 2008, p. 6). With Australia's most ruralised as well as high indigenous and low socio-economic state populations, Tasmanians' health is at considerably higher risk than other parts of Australia.

Tasmania has ten hospitals state-wide (1944 acute beds) (University Department of Rural Health [U.Tasmania] 2002, p. 4), however undergraduate training in most allied health professions (eg physiotherapy, occupational therapy, speech therapy, dietetics, audiometry, optometry) is not available within Tasmania. Undergraduate training for medicine, nursing, psychology, paramedic, pharmacy and social work is available via a single university (University of Tasmania), with three main campuses in the largest centres in each region (Hobart, Launceston and Burnie). Study or practice in certain sub-specialties generally requires temporary or permanent relocation to 'the mainland', and (as in other parts of rural and regional Australia) clinicians outside Hobart or the larger hospitals generally remain in more generalist roles (Pashen et al. 2007; Rosenthal 2010; Troyer & Lee 2010).

State-based providers of healthcare include the Tasmanian Government's Department of Health and Human Services (responsible for hospital and community health services via the Tasmanian

Health Organisations[8], as well as population health, children and youth services, Ambulance Tasmania, and disability, housing and community services) (Department of Health and Human Services [Tasmania] 2012a). Since 2011 the federally funded Tasmanian Medicare Local organisations (one in each of the three regions) have been responsible for "coordinating and connecting" general practice primary health care; including after-hours services, aged care, mental health, Aboriginal health, refugee health, chronic conditions, health promotion and e-health programs (Tasmania Medicare Local Ltd 2013). Preventive healthcare is also provided at primary, secondary and tertiary healthcare sites[9]. Australian healthcare is largely government (federal and state) funded, with "[m]ore than two-thirds of total health expenditure in Australia [in 2009-10] funded by government, with the Australian Government contributing two-thirds of this, and state, territory and local governments the other third" (Australian Institute of Health and Welfare 2012, p. 16).

Tasmanian epidemiology is particularly of concern where chronic conditions are at issue, given higher age-standardised mortality rates than Australia for cancer, diabetes mellitus, ischaemic heart disease, strokes and intentional self-harm (Department of Health and Human Services [Tasmania] 2013b, p. 3). Tasmania also had the highest mortality rate in 2011 of all jurisdictions apart from the Northern Territory (Department of Health and Human Services [Tasmania] 2013b). The most common chronic cancers are prostate, colorectal and lung cancers (males) and breast, colorectal and melanoma (females) (Department of Health and Human Services [Tasmania] 2008, p. x); 36% of the adult population are considered to have arthritis or musculoskeletal conditions (Department of Health and Human Services [Tasmania] 2008, p. x); and 15% of the Tasmanian population have "been diagnosed with a mental health or behavioural problem at some time in their life"(Department of Health and Human Services [Tasmania] 2013b, p. 9). In particular, DHHS note that "the prevalence of self-reported diabetes in Tasmania has increased by over 70% during the period 1995 to 2005, and hospitalisation rates for diabetes have more than doubled" (Department of Health and Human Services [Tasmania] 2008, p. xi) during the same time. In the same period, the Tasmanian male mortality rate for diabetes "more than quadrupled, whilst the female rate almost doubled" (Department of Health and Human Services [Tasmania] 2008, p. xi). Potentially preventable hospitalisations for all conditions "have not increased over the last decade", however hospitalisation rates have increased by 40% for males and 34% for females between 2002 and 2011, in particular for diabetes and

[8] At the time of writing, the three Tasmanian Health Organisations (North, North-West, and South) were about to become one state-wide Tasmanian Health Organisation (July 2015).

[9] Primary prevention targets the asymptomatic individual, secondary prevention those who have risk factors or 'pre-clinical' disease, and tertiary prevention the symptomatic and/or diagnosed individual (Wingarten & Matalon 2010, p. 138).

arthritis/musculoskeletal conditions (Department of Health and Human Services [Tasmania] 2013b, pp. 8-9). Potentially preventable hospitalisations are conditions where

> … hospitalisation is believed to be avoidable through the primary prevention, early detection and the provision of timely and adequate primary care for established conditions. … According to the method applied, only 6.7% of all hospitalisations in Tasmania were potentially preventable in 2010-11 – however, it is likely this proportion would be significantly higher were a broader definition to be used (Department of Health and Human Services [Tasmania] 2013b, pp. 8-9).

Developed-world concerns regarding chronic conditions are thus clearly reflected in the Tasmanian context.

Socioeconomically, Tasmania has a 'poor cousin' reputation within Australia, with the highest rate of unemployment (7.3%), the highest proportion of people living below the poverty line, and low Year 12 retention rates (36.5% completing in 2011) (Department of Health and Human Services [Tasmania] 2013b, pp. 24-25). Its poor standing on measures of social determinants of health[10] means that the Tasmanian population is inherently more at risk of chronic conditions, and that communities are less well resourced to address them.

Tasmania is therefore an excellent site for exploratory qualitative research into chronic conditions healthcare issues. Increased understanding of the experience of clinicians working within such communities is potentially useful, in that it may help determine factors which may impinge on clinical 'success' (for example, reduced hospital admission rates) in similar populations. As a clearly bounded rural and regional area with lower socioeconomic standing, Tasmania is useful as a lower socioeconomic, higher chronic conditions prevalence, first world case study; providing a convenient research site and sub-set of healthcare professionals with whom to reconnoitre the present conduct and experience of chronic conditions healthcare in lower socio-economic populations. As in similar high-income countries, Tasmanian healthcare access issues are as much determined by culture and norms of western healthcare and geographic separation as by extended physical distance (centralised services accessed by winding and sometimes icy roads, in some cases separated by water bodies). Studies of Tasmania may be thus be relevant to research into rural and regional UK and Europe, coastal and island areas of North America (including Canada), coastal Australia, and New Zealand more generally. While extrapolations from any qualitative projects should be made with caution; "the issues that are being addressed here are of universal significance, even if their specific manifestation has particularistic qualities" (Dempsey 1990).

[10] Key argument of the new public health movement, that "health is determined by social and economic factors": "social determinants of health are the causes of the causes of ill-health and emphasise social context, social stratification, the differential exposure people experience and their vulnerability to illness and injury" (Baum 2008, p. 590).

1.6 Summary

In this chapter I introduced the thesis, the type of research, my position and the research site. I proposed qualitative, interpretive methods as best suited to exploratory research involving multiple healthcare disciplines within a common focus of rural healthcare. I also acknowledged the necessity of incorporating strengths-based approaches, as well as deficit discussions. This chapter established that the experience of doing chronic conditions healthcare in a rural area is a common but neglected phenomenon, for health professionals akin to swimming midstream in a steady flow of chronic conditions. It identified three key validations for the research, namely that:

- chronic conditions are the dominant healthcare problem of our time;
- health worker demographics are changing;
- the cultural legacy affecting healthcare delivery preferences acute and emergency work over chronic conditions healthcare.

I outlined the research's interpretive, rural, strengths-based and multidisciplinary foci; and positioned myself - the researcher - as an integral factor in the type of research being undertaken.

Sociological studies of the experience of chronic conditions healthcare are insufficient and, of chronic conditions healthcare in rural areas, almost non-existent. As healthcare workers, healthcare planners and healthcare consumers, we need empirical evidence of the experience of working with people with chronic conditions in rural and remote areas, in order to address relevant issues and build on apparent strengths. May states that the

> … tremendous epidemiological explosion in chronic organic disease, pain, depression and mental-health problems … brings in its wake not only major changes in the distribution and experience of illness and ill-health, but also major changes in the experiences of professionals (May, C 2005).

This thesis explores and discusses the ways in which chronic conditions necessitate changed roles for healthcare professionals, and how the experience of that work for the clinicians is affected. Part One provides a review of the literature on chronic conditions, healthcare, and describes the method and methodology. Part Two reports the findings, identifying the practices associated with chronic conditions health care, and the structural factors that shape this work. Part Three discusses these findings in the context of existing theory and health care policy and practice.

The next chapters will explore relevant literature, in order to gain a deeper understanding of

(a) the conceptual and organizational settings for the research (Chapter Two), and

(b) the clinicians who do such work (Chapter Three).

Such understandings form a basis for exploring the experience of chronic conditions healthcare.

2 Chronicity and Chronic Conditions Theory

Chapter Two examines chronicity as a construct of chronic conditions theories. It looks at the dominant chronicity literature (chronic illness experience, from the patient point of view) and relevant theoretical frameworks (chronic illness trajectory, chronic care model, and chronic conditions self-management theories), which are partially derived from or influenced by chronic illness literature. It outlines Australian and Tasmanian approaches to chronic conditions management, and then provides a working definition of chronic conditions healthcare, as a basis for exploration of clinician experience of such work.

This chapter argues that historical imperatives biasing healthcare towards acuity have left an inadvertent legacy of bias against issues of chronicity. I concur with those who suggest that, with an epidemiological shift from acute to chronic predominance, patient roles are changing. However, I note that clinician experiences of the changed roles in chronic conditions healthcare are not documented.

I took a strategic approach to literature searching, as searching across multiple biomedical and social sciences database was required. The literature search strategy is discussed in the methodology chapter (Chapter Four); however, as appropriate to a qualitative study influenced by grounded theory, further literature was sought throughout fieldwork and research writing. I thought laterally when searching, as potentially fruitful key terms 'chronic disease', 'chronic condition*' and so on did not narrow the search sufficiently. 'Experience' generated largely patient perspectives; however 'rural practice' was to some extent fruitful.

As the research progressed, I sought more specifically relevant literature. The papers and books summarized here are those considered most relevant to this research, and I have prioritised those with issues or findings with transferability across professions, and within research conducted outside emergency and acute healthcare settings. I also highlight in-depth case studies (including first person accounts) and peer-reviewed research, over 'intelligent lay reader' and 'grey literature'; however I have included these where they were specifically relevant. Chapters Two and Three present the literature most relevant to the Research Question: 'what is it like, and what does it mean, to be a health professional doing chronic conditions healthcare?'

2.1 Chronicity

Chronicity (Larsen 2013a) is the defining 'sensitizing lens' (Glasser & Strauss 1968) through which the research in this thesis needs to be viewed, however it is not a word generally found in medical or nursing dictionaries. A typical medical dictionary defines the word 'chronic' as "persisting over a long time" (Dorland 2000, p. 351). Lay and biomedical definitions offered by the Oxford Dictionary describe 'chronic' as an adjective meaning

> "(1) (of an illness) persisting for a long time or constantly recurring", and
>
> "(2) (British informal) of a very poor quality" (Oxford Dictionaries Online & Oxford University Press 2013).

These different usages (biomedical and lay) and their implications (illness-related, 'problematic' and 'bad') are sometimes conflated by both healthcare professionals and patients. The connotations of chronic are thus almost invariably negative, and some people with chronic conditions describe feeling that the word 'chronic' has a derogatory flavour (Place 1992, cited in FitzGerald 1995, p. 4. See also Charmaz 1991; Atkins 2010). It is clear 'chronic' has both medical and lay meanings, and that these meanings are sometimes confused by lay users.

Discourse terminology is shifting, with 'long-term conditions' currently in favour (Hudson 2005{Margereson, 2010 #2809; Brooks et al. 2013)}, compared to (Madow 1967; Hasler & Schofield 1984; FitzGerald 1995; Toombs, Barnard & Carson 1995; Collins 1997; Wagner 1998; Holman, H 2004; Institute for Healthcare Improvement 2005; Wakerman et al. 2005; Lubkin & Larsen 2006; Australian Institute of Health and Welfare 2008; Roberts & Lalor 2008; World Health Organization 2012). The social and cultural meanings associated with 'chronic', which may potentially be attached to 'long-term conditions' in the future, are of relevance in undertaking this research. This research commenced planning and fieldwork using the term 'chronic conditions' exclusively, influenced by Frendin's Australian Journal of Primary Health editorial (2003), and maintains this. Whilst 'long-term conditions' reduces confusion between lay and biomedical meanings, as a thesis focused on health professional experience and understandings, this thesis uses 'chronic conditions', as the terminology most commonly used and understood by the present Australian clinicians whose views and experiences were sought.

Chronicity is therefore a noun denoting 'that which incorporates any long-term experience', and in this thesis relates to qualities of ill-health. Chronicity itself has one major defining characteristic: the extended temporality of long duration illnesses. However an extended timeframe is not always made clear at initial diagnosis. The AIHW defines chronic diseases as those "that are prolonged in duration, which do not often resolve spontaneously, and which are

rarely cured completely" (Australian Institute of Health and Welfare 2013). Yet, as Habibis states, "when people initially seek medical help for a condition that turns out to be chronic, they often have no idea that it will be a semi-permanent state and may not even have identified that they have an illness" (Habibis 2009, p. 292). The temporality of chronic conditions is potentially intermittent as well as extended, and often contested or denied, by patients as much as (even more than) by health professionals.

Another aspect of chronicity is its uncertainty, with chronic conditions spanning the range of mental and physical conditions of all organ systems, and also spanning a range of causes (such as genetic predisposition, developmentally induced, injury-related, immune system mediated, and so on). The Australian Institute of Health and Welfare suggests that chronic diseases are those "characterised by:

- complex causality
- multiple risk factors
- long latency periods
- a prolonged course of illness
- functional impairment or disability" (Australian Institute of Health and Welfare 2013).

Their symptomatology, prognoses, and impacts are thus equally wide ranging; with some conditions' mechanisms and treatments well researched and understood (for example, congestive heart failure), while others are more complex and contested (such as diabetes with its shifting diagnostic criteria and multiple organ systems involvement, or chronic fatigue syndrome where diagnosis, treatment and even the condition itself are disputed). Many long-term conditions have effects on different body systems, and thus require treatment from many different parts of the health sector (for example diabetes may generate consultations in general practice, endocrinologist, podiatrist, optometrist, and dietician settings).

Equally, some chronic conditions can be immediately life-threatening, others "can persist over time and can be intensive in terms of management", but many "persist in an individual through life, but are not always the cause of death" (Australian Institute of Health and Welfare 2013). The temporality, complexity, ambiguity and contingency of chronicity, and subsequently of chronic conditions healthcare, are discussed in Chapter Eight.

2.2 Seminal chronicity literature

Chronic conditions have not been entirely neglected; however the majority of work is 'illness experience' literature (particularly illness narratives), and only a limited number of chronic

conditions theories appear to have gained a foothold in clinical practice. Habibis notes much of the lay perspectives work within health sociology is based on chronic conditions experience (Habibis 2009, p. 291). Chronic illness experiences, and the interplay of chronicity with traditional conceptualizations of Talcott Parsons' 'sick role' (Abercrombie, Hill & Turner 2000, p. 314), are thus important to understanding of chronic conditions; and will be discussed in Section 2.3.1. In addition, chronic illness literature has influenced the styles of research and writing encompassed within this research. This literature review will address patient perspectives and experiences of chronic illness first, before outlining theoretical perspectives on chronic conditions in Section 2.4: Glaser and Strauss's Chronic Illness Trajectory model, Wagner's Chronic Conditions Model, and some chronic disease self-management (CDSM) theory. Chronic conditions practice in Australia is then explored (2.5), and a working definition of chronic conditions healthcare constructed (2.6).

2.3 The Chronic Conditions Experience

Health sociologists and clinician advocates for patients have long argued for increased attention to patient stories, and to social and cultural dimensions of illness experience rather than solely biomedical and disease foci (eg Roth & Conrad 1987; Anderson & Bury 1988; Hahn 1995; Kleinman 1998). What the 10th Global Conference: Making Sense Of Health called 'the borderlands', "the spaces between health and illness that chronic patients occupy" (10th Global Conference: Making Sense Of Health 2011), are still not well defined or well understood territory. Patient perspectives remain marginalised in current healthcare planning, an "adjunct to the 'real game', [i.e.] the disease" and "a parallel discourse to medical accounts of illness and disease" (Buttfield 2011, p. 7). The experience of chronic illness itself, while not the central focus, is nevertheless important to this thesis. The experiences of people with chronic conditions shape the work of healthcare professionals - and therefore healthcare professional experiences of doing long-term conditions work.

2.3.1 Chronic Illness Experience

The nature of chronic conditions is to be uncertain and cyclical (recurring), and often involves periods of wellness as well as illness. Fatigue is also a crucial aspect of many chronic conditions, for example as a side effect of medications, or of pain (see Margereson, Martin & Duffy 2010, p. 98). Experiences of being ill or disabled are well chronicled in book form narratives (for example Atkins 2010; Edwards 2008; Karp 196; Sacks 1984), as well as more recent 'sick lit' blogs; such as Paula Kamen's migraine blog (Kamen n.d.) Jenni Prokopy 'chronicbabe' (Prokopy n.d.) Sandi Wisenberg 'cancer bitch' (Wisenberg n.d.). More sociological analyses of people's experiences

with chronic conditions (Thorne 1993; Frank 1995; Kleinman 1998; Davis & Magilvy 2000; FitzGerald, Pearson & McCutcheon 2001; Bury 2005 [1982]; Edwards 2013) generally conclude with calls for healthcare systems to better support patient autonomy.

Kathy Charmaz produced one of the seminal books of illness experience, Good Days, Bad Days (Charmaz 1991), and noted that "[t]he acute illness and care model inherent in the concept of the 'sick role' is shared by many practitioners as well as patients" (Charmaz 1991, p. 280). Review of the relevant literature indicates the role of the patient, or 'sick role' as Talcott Parsons construed it, has never truly applied or been wholly accepted in the context of some chronic conditions (see Jones 1994; Lupton 1994; Loewe et al. 1998; Fältholm 2010; Mik-Meyer & Obling 2012). The sick role concept was outlined by Henderson (1935) and expanded by Parsons (1951); and suggests that when sick, an individual:

> (1) … is exempted from normal social responsibilities;
> (2) … is not blamed for being sick;
> (3) … is expected to seek out competent professional help […];
> (4) … is expected to comply with the regimen prescribed by a competent physician. (Abercrombie, Hill & Turner 2000, p. 314)

'Normal' aspects of the sick role, such as suspension of normal duties and reduced/eliminated blame for illness, are clearly more complex for people with intermittent or slowly progressing chronic conditions. Where conditions continue indefinitely, any reduction of duties (as for someone acutely unwell) is complicated. 'Help-seeking behaviours' are also complicated by the long term and intermittent nature of chronic conditions: 'if it ain't broke, don't fix it' assumptions may lead to complacency during apparent health or long latency, despite the diagnosed presence or impending diagnosis of a long-term condition. People with chronic conditions thus potentially violate what Goffman, Illich, Parsons and Zola cast as the stigmatizing, colonizing or normativizing rhetoric of health (Metzl 2010), where 'health' is

> "a term replete with value judgments, hierarchies, and blind assumptions that speak as much about power and privilege as they do about wellbeing. Health is a desired state, but it is also a prescribed state and an ideological position […] 'Health is seen as an unqualified good. Who can be against 'health'?' " (Jackson, cited Metzl 2010, p. 2)

Atkins' work on Medically Unexplained Physical Symptoms [MUPS] demonstrates that "the pursuit of 'disease'… structures one's perception of an ailment" (Atkins et al. 2013, p. 4). People with complex chronic conditions, diagnostic uncertainty, or medically unexplained symptoms may find that, "in contrast to 'authentically' sick people, patients with symptoms but no 'real' disease can be labelled and stereotyped as 'trolls' and 'crocks'", rendering clinicians "less vigilant, thorough, and caring" (Caldicott 2007, p. 139). It may be that unconscious expectations of both

immediate family and healthcare professionals are that a person is either sick or well, but not both simultaneously, or in rapid alternation (as in many chronic conditions).

Motivation to pursue either cure or symptom palliation appears somewhat dependent upon an episode being sufficiently intrusive to motivate (at least partial) action. It is possible that chronic conditions are easier to disregard, given 'normalization' of poorer health, and the exhaustion of constant experience leading to a lack of motivation to pursue better health. Stimson et al suggest that a patient needs to be seen as a "participant in medicine, rather than simply a recipient of medical care" (cited Annandale, Elston & Prior 2005, p. 4). However they noted that although patients can exert control in deciding whether to present for treatment and choosing to follow treatments, such strategies were "small scale and individualistic" (Stimson et al., cited Annandale, Elston & Prior 2005, p. 4).

The 'sick role' function of seeking help from a health professional (actually a healthcare professional or illness treatment professional) is thus only an *elective* function for many people with chronic conditions: an optional action rather than a necessity. The role of the healthcare professional is complicated by the volitional nature of help-seeking behaviour. First, a patient may need to be convinced that they need to be medicated at all. A drug can then be started and raised to the point of maximum efficacy, continuing on this path for a number of months, then (if side-effects become increase or intolerable) another drug may be added to counteract side effects. The second drug may have different side effects which need intervention, or the initial drug may need 'tapering down' whilst adding or increasing another in the hope of similar effects, and so on. The trajectory of treatment thus becomes a complex, many-stranded rope of multiple interventions *with the recommendations for each treatment contingent on each other*. The health professional and chronic conditions patient may be titrating:

- drugs
- exercise regimes
- sleep hygiene / sleep management
- cognitive behavioural therapy and/or meditation programs for any concurrent depression or anxiety (nb psychiatric comorbidity is common with many chronic conditions)
- visiting nurses (wound management)
- allied health appointments for specialist support (such as a dietician, optometrist, physiotherapist or exercise physiologist)

- specialist reviews.

All this may occur with or without formal psychosocial support (eg psychologist or social worker) for the patient and his/her carers; and without social vindications normal to acute illness. The chronic conditions sick role is now a part-time, casual or temporary role; without standard occupational benefits.

Where the sick role is problematized, the role of the healthcare professional is also brought into question. The experience of being labelled, and potentially stigmatized, by clinicians is also common to many people with chronic conditions. Patients who invalidate "clinicians' sense of themselves as effective professionals, … and/or who create fruitless work[,] are subject to being labelled as 'bad patients' " (Hill, T 2010). Bernstein (partly ironically) describes:

> …the ideal patient … has real physical symptoms, one acute disease - not confusing multiple new diseases at the same time and, finally, clear cut physical findings and lab tests. The illness, hopefully, would have standard treatment which is virtually universally satisfactory and the risks of treatment being minimal, if at all. The patient should be alert, in good spirits (not too sick), have confidence in the physician, readily competent to make decisions, thoroughly interested in learning about the illness and its treatment and willing to take time to listen carefully to the explanation by the physician and the options of further diagnostic tests and treatment. And when it comes to treatment, the ideal patient will make the effort to follow the physician's prescription directions and remain fully compliant. The patient will also carefully monitor their reaction to the medication and promptly report to the physician any side-effects or complications. The ideal patient will also have the ideal family. Such a family will support the patient but also show confidence in the physician and support the physician (Bernstein 2004).

According to Rosenthal et al, a similar viewpoint is traditionally part of nursing, whereby, ideally

> … from a nurses' perspective, all patients should be sick when they enter the hospital, should follow eagerly and exactly the therapeutic programme set up by the staff, should be pleasant, uncomplaining, fit into ward routines, and should leave the hospital 'cured' (cited Jones 1994, p. 499).

Such 'ideal types', as construed by Weber (see Germov 2007), give good indications of the cultural expectations that come with the label 'patient'.

The capacity of the patient to be cured offers some clinicians a sense of efficacy, however 'curability' is absent in most chronic conditions, and the professional sense of efficacy potentially equally absent. Not all chronic conditions are 'incurable'; but most are, by definition, of long duration. In addition, in some chronic conditions the healthcare professional is not only 'optional' (must convince the patient of the necessity of their use and function), but also cannot be guaranteed to 'make a difference', an experience which clinicians sometimes link to their own competence or sense of efficacy. Horowitz et al studied meaningful professional experiences for

medical practitioners, and noted that despite finding meaning in "the context of chronic, incurable conditions, or end-of-life care", "doctors were often surprised to be thanked in the absence of cure or significant improvement" (Horowitz et al. 2003, p. 773). This view concords with Atkins et al who note that, where no clearly definable disease entity exists, "uncertainty is a stress" within medical practice (Atkins et al. 2013, p. 4).

The rise in and importance of patient experience literature cannot be underestimated, as it parallels cultural shifts including those of balance within healthcare systems - from structures focused to some degree on the maintenance of professional autocracy (clinician 'power over' patients), to more patient-focused ('power with') approaches. However, in most chronic illness literature, clinicians play bit parts (supportive, intrusive, or simply bearers of news). Negative experiences with health professionals and/or healthcare systems are often prominent; yet the main focus of chronic illness experience literature is on living with and self-managing chronic conditions. Almost all patient-centred accounts call for clinicians to prioritise chronic illness experience and meaning within their care (see Charmaz 1991; Frank 1995; Fox 2003; Atkins 2010), although clinicians' views on this (for example, existing attempts to do so) are largely absent.

2.3.2 Health Professionals as Patients

Another set of illness experience literature does take a health professional view into account. The experiences of health professionals who have become patients form a separate subset of illness experience literature (eg Wiitavaara, Barnekow-Bergkvist & Brulin 2007{Kleinman, 1998 #860; Sacks 2010). These health professional experiences of illness are useful in that the style of analysis, both of self and healthcare system, is somewhat different to that of 'lay' people who become patients. Additionally, there is some documentation of health professionals' experiences of becoming carers or major support (life-partners) for someone with a chronic condition (eg Simms 2009; Larsen 2013b), and how this impacts on their professional work. Some healthcare professionals describe increased empathy, concluding "being a patient is hard work" (Thomas 1983, cited Hahn 1995, p. 251), or "I've been through this myself … I know what it's like" (surgeon visiting Sacks 1984, cited Hahn 1995, p. 246). Some remain "essentially unchanged" by their illness, while others consider they have "transformed their self-identity", becoming "empathetic advocates … as a result of being ill or caring for a family member", as demonstrated in a qualitative study of pharmacists' illness experiences and the effects on pharmacist-patient relationships (Sinnott 1997). Such data is useful to my research, as it demonstrates the impacts of personal experience of illness on practice style.

Dunning investigates the effects of chronic stress in general, and discusses clinicians as 'wounded healers' in examining self-care routines for herself and others as clinicians (Dunning 2006, see also Kleinman 1998, p. 211). Klitzman mentions 'having to be strong', 'under-accessing care', 'not practising what they preach', and 'white coat immunity to illness', as doctor-specific attitudes, which were sometimes helpful in treating patients, however were obstacles to experiencing their own illnesses (2006). However Hahn's chapter exploring physicians as patients, 'between two worlds', offers in-depth coverage of fourteen accounts of physicians experiencing illness or trauma (1995). He outlines some aphorisms ('physician, heal thyself', 'doctors make the worst patients'); before exploring physician experiences common to other patients, of encountering and 'bearing' affliction, in addition to 'depersonalization' ("great case") by insensitive colleagues (Hahn 1995, pp. 234-261). He also offers a 'course' he considers partially shared by physician patients and non-clinician patients:

1. The damage is initially seen as someone else's.
2. It is minimized.
3. It is intellectualized, transformed into a subject for writing and teaching.
4. Physician patients diagnose their own conditions.
5. They may treat themselves and they may delay in seeking treatment by others.
6. They evaluate the diagnoses, prognoses, explanations, treatments, and care given by their colleagues.
7. They mistrust some of their physicians or their physicians' diagnoses, therapeutic prescriptions, or prognoses.
8. They discover a special need for understanding, explanation, support, and sympathy from colleagues, beyond what is strictly 'medical'.
9. They strive to have non-'crock'-like conditions and to be 'good patients'.
10. They strenuously avoid passivity and lack of control.
11. They recall other patients whom they may have misunderstood or who may have had severe side effects with conditions similar to their own.
12. They continue to monitor themselves, medically hypervigilant for signs and symptoms indicating possible changes in their conditions.
13. They re-examine themselves and their histories in the search for etiology and broader explanation.
14. They reformulate their theory and practice of medicine in the light of their patienthood (Hahn 1995, pp. 257-258).

Internal 'professional identity' obligations appear to force clinicians who become ill to self-monitor to a greater extent than the average individual. Clinicians also depict the contrast

between clinical autonomy and patient restriction more sharply: Sacks in recounting the "systematic depersonalization" of hospital gowns and identification bracelets, or Geiger as below:

> At one moment I was a physician: elite, technically skilled, vested with authority, wielding power over others, affectively neutral. The next moment I was a patient: dependent, anxious, sanctioned in illness only if I was cooperative. (Geiger 1975, cited Hahn 1995, p. 238).

The experience of transitioning from clinician to patient is sometimes less abrupt in gradual onset chronic conditions, although not always, noting that many experiences of chronic conditions commence with an acute event (such as a heart attack or stroke).

Hahn's 'course' has some attitudinal commonalities with the more utilised chronic conditions trajectory (which is discussed below), despite being constructed in response to traumatic injuries as well as long-term conditions. However, both the chronic conditions trajectory and Hahn's clinician-patient 'course' specifically focus on patient experiences and trajectories within chronic conditions healthcare. This research explores clinician experiences of chronic conditions healthcare, with or without personal experience as a chronic conditions patient.

2.3.3 Rural Experience of Chronic Illness

As noted, of particular interest to this research is the impact of rurality on the experience of chronic conditions. While there is a great deal of 'grey' and anecdotal literature advocating for patients and thus detailing their experiences, there is little academic literature dealing specifically with rural experience of chronic illness. An exception is FitzGerald, who documents difficulties for rural Australians with chronic conditions in finding the right doctor, travelling to medical/paramedical appointments (for example, specialists, allied health which are often further away than normal GP distances), and maintaining a chosen rural lifestyle (FitzGerald 1995; FitzGerald, Pearson & McCutcheon 2001). Remote Australians in particular have to travel and in some cases move to larger rural centres, in order to access treatment which improves or maintain their health within their chronic conditions (such as for regular dialysis treatment (see Office for Aboriginal and Torres Strait Island Health [Australian Government] 2002; Wakerman et al. 2005). The subsequent incapacitation of family connectedness, and/or inability to complete 'family business', puts particular pressure on more isolated rural and remote communities.

Other studies note effects such as 'physical and emotional isolation', 'maintaining balance', 'uncertainty', 'vigilance' and 'ways of coping' (Winters & Sullivan 2010); and 'managing daily', 'support from faith and family', 'balance through negotiation', 'self-care', 'belonging to community', and 'finding meaning in life' (Davis & Magilvy 2000) as themes in rural chronic

illness experience. Such windows into experience of chronic conditions for people in rural areas may also provide windows into the experience of rural health professionals.

2.3.4 Chronic illness and changing patient roles

Chronic illness narratives have at least partially (if not wholly) influenced a shift in patient role. Despite the peripheral position of patient perspectives and self-management approaches within biomedical discourses, a shift from passive consumer to active participant in healthcare has been tracked over the twentieth century (eg Porter 1997; Pound et al. 2005). Irrespective of self-management approaches (discussed later in this chapter), expectations of the patient role have risen: with tasks like disease monitoring, biomarker testing, medication regime adjustment, communicating changes to all members and consultants on the patient's 'healthcare team', and lifestyle management (notably weight loss, dietary management and exercise) all part of *patient* as well as clinician chronic condition work.

Seear describes the work of being an expert patient as a 'third shift' (Seear 2009), referencing Hochschild's concept of first (paid) and second (unpaid) shifts within the lives of working parents. It is worth noting rural clientele may already be operating multiple shifts, with rurality a further 'shift' to manage (commute times, access to economic and health infrastructure) in the complexity of day-to-day lifestyle management. Equally, metropolitan commuting and costs of living may constitute the makings of a further 'shift' for urban cohorts. The chronic conditions patient must therefore exercise considerable agency, in deciding whether to (when to) attend healthcare services for a clinical consultation, as well as which, if any, parts of recommended treatments to comply with. In reality, patients rather than healthcare professionals do the majority of chronic conditions work. Corbin and Strauss note:

> [W]hen one looks closely at how management is carried out over the years of an illness, it is clear that very little of it takes place in hospitals, rehabilitation centers, or other health facilities. Most of the day-to-day management takes place in the home and is carried out by the ill person and/or family" (Corbin & Strauss 1991, p. 159).

People with chronic conditions manage day-to-day symptoms and functioning; medication decisions, availability and usage; and lifestyle modifications - the extent of which visits to health professionals only partially document.

In the late twentieth century there has largely been a sliding scale of patienthood, shifting from objectified site of organic pathology in some parts of the health system, towards experienced individual subjectivity (negotiating, accepting or denying treatment) in others. What Coleridge

categorises as an attitude of doctors as "shallow animals [… who] imagine that in the whole system of things there is nothing but Gut and Body" (Porter 1997, p. 8), or (more contemporaneously) where "hospital medicine put the subjectivity of the patient to one side" (May, C et al. 2006, p. 1024), has perhaps never been particularly characteristic of attitudes to patients in community based primary care. Where hospital intensity and higher numbers of patients with similar conditions and presentations encourage objectification and categorisation ('the diabetes in Bed 4'), clinicians in community contexts have struggled to incorporate the lived experience of patients into their practice since before the First World War (Cox 1950, cited Bardenhagen 2004; Öhman & Söderberg 2004; May, C et al. 2006, p. 1024; Keleher et al. 2007b).

Where life-threatening conditions do not demand immediate attention, Holman suggests two issues are "intrinsic to the provision of health care": "the emergence of chronic disease as the dominant healthcare problem" and "the changed role of the patient" (Holman, H 2005). The second issue is foundational to many of the approaches presently pitched as solutions to the first:

> With acute disease, the patient is usually inexperienced and passive while the physician applies treatment and cure is achieved. With chronic disease, in the absence of cure, the patient must carry out treatment and adjust to the many impacts of chronic handicap over an indefinite time. Thus the patient becomes a central care-giver in the continuing process of managing a chronic disease (Holman, H 2005).

Someone seriously ill with acute appendicitis has little capacity for agency (and indeed, few options, most of which must be provided or sourced externally to the patient; for example, surgery or intravenous antibiotics). The issue of agency becomes a matter of choice of hospital or (maybe) surgeon. However someone with mild diabetes has many options. Some of these options require more patient effort than a simple arrangement of external provision; for example, change of diet, increasing or changing to appropriate forms of exercise, which or how many medications to be taken. Such patient actions may modify immediate as well as long-term outcomes (such as whether there is a need to commence drugs, to commence additional drugs, or modify current dosages). Equally, patient activity may modify side effects experienced from existing drug regimes, and potentially affect the need to take drugs to ameliorate side effects.

The project of 'becoming a patient' takes on moral overtones, with a certain amount of victim blaming inherent. While healthcare professionals may not openly espouse views such as 'if you only exercised/dieted, you wouldn't have diabetes', it is very hard to operate independent of cultural norms around health-seeking behaviours. Equally, a person with intermittent mild asthma may have more inherent agency (more energy to make choices or take preventative action, wider range of therapeutic options) than someone who is permanently unwell (breathless

daily despite medication usage, and feeling unable to exercise). Charmaz identifies chronic illness as potentially functioning as *interruption* (for example, periodic migraines or menstrual cramps, with significant but intermittent or time-limited disability), *intrusion* (such as multiple sclerosis or Parkinson's, with progressive degeneration and increasing frequency and duration of intrusions), or *immersion* (where a condition has progressed sufficiently that disabilities are permanent) (Charmaz 1991). The first two of these categories reflect the dominant understanding that 'people are generally looking for recovery' (temporary or permanent): that the illness state is thus the aberration from normal, as suggested by Talcott Parsons and elucidated by Zola:

> Born for the most part into normal families, we are socialized into that world. The world of sickness is one we enter only later, poorly prepared and with all the prejudices of the normal. The very vocabulary we use to describe ourselves is borrowed from that society. We are de-formed, dis-eased, dis-abled, dis-ordered, ab-normal and, most telling of all, called an in-valid. And almost all share deep within ourselves the hope for a miracle to reverse the process, a new drug or operation which will return us to a life of validity (Zola, cited Barnard 1995, p. 42).

The cultural norms of 'wellness' thus create a particular kind of stigma for people with chronic conditions (see Bury 1982, Thorne 1993, Atkins 2010). The chronic conditions end of the 'sliding scale of patienthood' may be experienced as either intermittent encounters with patienthood or as permanent status. However, intermittent and ongoing 'patienthood' impacts on styles of engagement with healthcare professionals, and thus on healthcare professional styles of engagement with patients. Patient agency may be dependent on trajectory stage, but also shapes clinician agency. Literature about the agency and experience of clinicians in doing healthcare work is addressed in Chapter Three. However, through immersion in the chronic illness experience literature, I began to understand that many people with long-term conditions consider themselves well for substantial periods of time, with intermittent relapses or degenerating periods, followed by partial recovery and return to what they perceive or experience as normal health and wellbeing status.

2.4 Chronic Conditions Theory

2.4.1 Chronic illness trajectory framework: Strauss and Corbin

One of the more utilised theoretical models is Strauss and Corbin's chronic illness trajectory framework, formulated as one of the first theoretical frameworks, which examined chronic conditions beyond illness specific biomedical models (Corbin & Strauss 1991). In its early development, its primary tenet was that "chronic conditions have a *course* that can be shaped through proper management", later referred to as an illness 'trajectory' (Corbin & Strauss 1991, p. 157, emphasis added).

The longitudinal nature of chronic illness activity means that "different trajectory phases (crisis, acute, stable, comeback, unstable, downward, and dying)" are experienced, "as well as the differences in problems and management associated with each phase" (Corbin & Strauss 1991, p. 159). In addition, "chronic illnesses present certain everyday living problems (like managing regimens, reordering time, living with isolation, and so on) that must be managed if the ill and their families are to experience any sort of quality of life" (Corbin & Strauss 1991, p. 158).

While primarily based on nursing research and taught in nursing undergraduate chronic conditions subjects, the chronic conditions framework is promoted as applicable across disciplines and can be seen as influential in major policy development (eg National Health Priority Action Council & Department of Health and Ageing [Australia] 2006 also Wagner's Chronic Care Model as discussed below). Burton asserts "[t]he key to the utility of the framework lies in the assumption that although each individual with a chronic illness experiences the disease process in a unique way, there are common phases which involve changes in health status and intervention need" (Burton 2000). Corbin and Strauss thus attempted to refocus chronic illness discourse:

(1) towards patient experience outside intensive healthcare settings, and

(2) towards longitudinal pathways.

These tenets shape this research (form part of its conceptual framework) in two ways.
First, the research primarily takes place largely *outside* intensive intervention settings (such as hospitals and nursing homes): in community-based settings such as general practice, private homes (with visiting health professionals), pharmacies, and outpatient or community 'clinics'.
Second, this research investigates the longitudinal pathways of health professionals, in parallel with the trajectories of their patients.

Frustratingly, the general impact of the chronic conditions trajectory framework appears limited, perhaps profession-specific, and generational (largely understood only within nursing, and only by more recently trained nurse graduates). Whilst similar concepts are mentioned within some policy documents, explicit clinical awareness (irrespective of utilisation) of the chronic illness trajectory as an intellectual concept or clinical framework is unclear. Nevertheless, in changing understanding of the ways illness needs to be worked with, the chronic illness trajectory has had profound implications for our understandings of illness experience.

2.4.2 Chronic Care Model (Wagner et. al)

Chronic condition care models, unlike traditional understandings of the sick role, clearly take the intermittent and prolonged nature of many chronic conditions into account. The gold standard in care models is the Chronic Care Model (CCM) developed by Wagner (Wagner 1998) "is widely used in policy forums" (Dennis 2009), and suggests that six elements are crucial to long-term conditions management:

(1) community resources and policies,

(2) health care organisation,

(3) self-management support,

(4) delivery system design,

(5) decision support and

(6) clinical information systems (Bodenheimer, Wagner & Grumbach 2002, p. 1776).

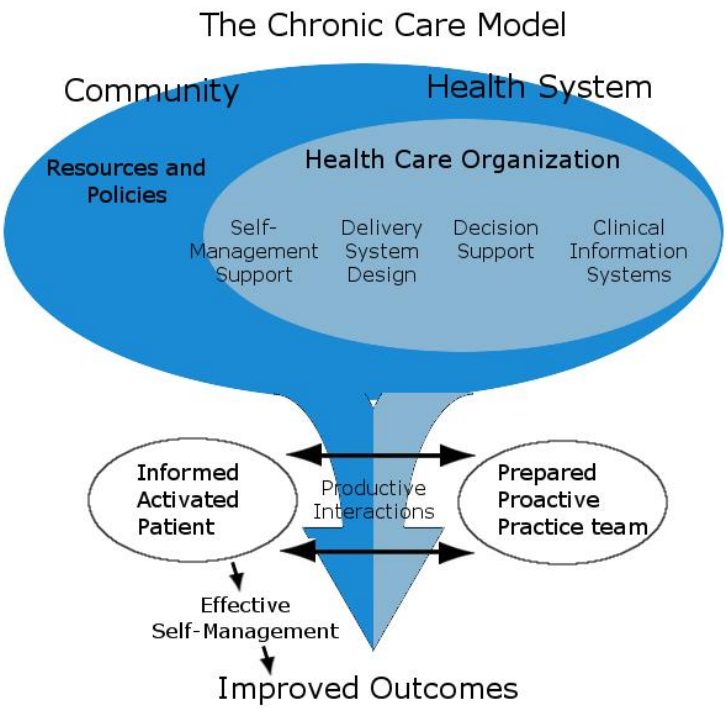


Figure 1: The Wagner Chronic Care Model (as cited Department of Health and Human Services [Tasmania] 2009, p. 56).

This approach notes the components "are interdependent", and that only multifactorial solutions can address the complexity inherent in long-term conditions (Bodenheimer, Wagner & Grumbach 2002, p. 1776). An Australian systematic review (Zwar et al. 2006; Dennis et al. 2007; Dennis 2009) used the Chronic Care Model (Wagner) as a framework for analysis, and looked at

the effectiveness of chronic disease management in the primary care setting in Australia and comparable countries (USA, Canada, UK, Netherlands, New Zealand, Scandinavia). It concludes self-management support and delivery system design impacted on patient outcomes (especially in diabetes), and that decision support and clinical information systems improved health professional adherence to guidelines (Zwar et al. 2006, p. 60). However that there was:

> … little evidence for changes in health care organisation and community resources because they are difficult to assess experimentally […] but in the real world may be of considerable importance (Zwar et al. 2006, p. 61).

More recent international research is similarly conflicted, with

> moderate evidence… for a beneficial effect of comprehensive care on inpatient healthcare utilization and healthcare costs, [but] insufficient evidence … for a beneficial effect of comprehensive care on health-related quality of life in terms of mental functioning, medication use, and outpatient healthcare utilization and healthcare costs (de Bruin et al. 2012).

Nevertheless, the Chronic Care Model provides a useful background in terms of issues which need to be considered in constructing research into the experience of long-term conditions work.

2.4.3 Chronic conditions self-management (CCSM)

For the duration of this research, most discussions on approaches to long-term conditions focused on chronic conditions self-management (CCSM) programs as an appropriate response. While they are not the focus of this research, and indeed, do not currently form the bulk of clinical work with people with chronic conditions, the increasing prevalence of self-management approaches in both policy and practice requires a brief overview. The Tasmanian Department of Health and Human Services defines self-management as

> the active participation by people in managing their own health […, incorporating] health promotion and risk reduction, informed decision-making, care planning, medication management and working effectively with healthcare providers to attain the best possible care and to effectively negotiate the often complex health system (Department of Health and Human Services [Tasmania] 2009, p. 27).

Similarly, Margereson et al describe the five core skills of self-management as

- problem-solving,
- decision-making,
- resource utilisations,
- developing effective partnerships with healthcare providers, and
- taking action (Margereson, Martin & Duffy 2010, p. 97).

Active self-management usually incorporates personal acceptance of a level of sickness ('sick role') which demands intervention (biomedical- and self- prescribed) and generally adherence to some level of professionally prescribed and personally tested/refined treatment regime. Self-

management is generally considered a step beyond 'self-care' (also known as 'activities of daily living'. Self-management activities may or may not include patient-clinician collaborative approaches to medications, exercise, diet, psychological work (such as mindfulness meditation and/or mood management), pain and sleep management tactics, and complementary or alternative medical treatments.

A number of different CCSM support approaches exist, including the Chronic Disease Self-Management Program (aka 'Stanford', aka 'Get the Most Out of Life') developed by Lorig (USA), the Expert Patient program (NHS, UK) and the Flinders model (Aust.). The shift towards patients as partners in treatment has been extended by programs like the UK National Health Service's 'Expert Patient', a "small, but in policy terms important" programme of group work (peer and health professional co-led) introduced in 2001 (see Taylor & Bury 2007; Greenhalgh 2009; Lindsay & Vrijoef 2009); and developed from Lorig's Stanford program (Lorig 1994). Techniques that incorporate self-management style approaches and are utilised in Tasmania at present include the Stanford and Flinders models, Health Coaching (Gale 2010) and Motivational Interviewing (Mesters 2009; Pollak, Childers & Arnold 2011). Tasmanian-developed CCSM programs (Appetite for Change, CENTR'd, Pathways to Health) are discussed in a later section.

Self-management techniques have been criticized as reliant on highly motivated patients who already have existing capacity to self-manage (eg Lindsay & Vrijoef 2009). The clear increase in illness narratives appears to have shifted theoretical focus to 'self-management' and 'expert patients' within clinical situations; and ways to encourage people (both patients and health professionals) to either take or reinforce this style of role. Glasgow et al consider self-management and self-management support as "key aspects of optimal chronic disease care, and … effective if implemented appropriately." (Glasgow et al. 2008), and systematic reviews already discussed (Zwar et al. 2006; de Bruin et al. 2012) find some supportive evidence. Conversely, other evidence suggests "alternative forms of support may produce comparable outcome improvements" (Lindsay & Vrijoef 2009, p. 140).

While chronic illness, experienced over many years, does to some extent make an expert of a patient, each patient remains experienced in their singular manifestations of a particular constellation of chronic condition(s), rather than an expert in broader prognostic patterns. Not every patient can be an 'expert patient', an empowered self-determiner, and some are concerned that no patient should be perceived as an 'expert' *per se*, in understanding of "the generalisations that underlie reliable clinical treatment" (Badcott 2005). Wilson et al also express concerns that,

rather than empowering patients, self-management programs can reinforce the medical model and therefore more traditional patient-professional relationships (Wilson, Kendal & Brooks 2007).

Greenhalgh's review of the National Health Service (UK) Expert Patient program notes limited health improvements, the difficulties of recruiting and engaging people with low health literacy, concludes "the evidence base for their efficacy is weak", and that policy needs to "embrace richer, more holistic models which consider a person's family, social, and political context" (Greenhalgh 2009, p. 631). Taylor and Bury express a concern that self-management initiatives ("implementation programmes focused more on changing individual behaviours and ways of thinking") "may run the risk of 'blaming the victims' rather than addressing the social factors more fundamentally responsible for their illnesses" (Taylor & Bury 2007, p. 32). Others believe that the nature of self-management programs (in particular self-selection processes) attract less compromised, more physically and emotionally able participants, thus missing more needy target groups (see Greenhalgh 2009; Lindsay & Vrijoef 2009). The possibly gender specific nature of self-help groups has been commented on, with women more likely to participate (Lindsay & Vrijoef 2009). Geographic access to programs also poses an issue (Bell & Orpin 2006). Lindsay concludes "there are serious gaps in understanding and improving disease self-management because of an emphasis on clinical settings and neglect of social environmental factors" (Lindsay & Vrijoef 2009, p. 141).

While CCSM approaches do not provide a singular solution to the multi-factorial issues of chronic conditions, Taylor and Bury argue that self-management programmes and related 'care transition' initiatives have implications "for the future identities and working practices of health professionals such as general medical practitioners, nurse and community pharmacists" (Taylor & Bury 2007, p. 29). At the very least, for healthcare professionals, it is assumed that more autonomous patients may demand a new style of engagement during consultation. Lindsay suggests that "relatively little is known about the impact of 'expert patients' on health care providers", with "more work… needed to explore how expert patients influence physician autonomy, patient-provider relations, workload and job satisfaction" (Lindsay 2007, cited (Lindsay & Vrijoef 2009, p. 140).

With chronic conditions self-management currently peripheral to the majority of healthcare provision, in undertaking this research I remain focused on chronic conditions healthcare as a whole rather than on self-management. However, with CCSM approaches influencing policy and

practice, this research does capture some interviewed clinicians' responses to the rise of CCSM (see Section 5.3.1). However, whilst self-management forms a significant and potentially increasing area of chronic conditions management, it is by no means the complete picture. I believe that with only a small number of health workers presently trained in and undertaking self-management support, there are presently other ways of doing chronic conditions healthcare which need examination. In this thesis, I unearth the broad range of chronic conditions healthcare approaches and activities rural health professionals are presently involved in, rather than limiting the research scope to one style of chronic conditions work. In doing this, I stay true to the Research Question: what is it like to be a health professional doing chronic conditions healthcare?

2.5 Chronic conditions practice

Chronic conditions practice is clearly informed by both patient experience and theoretical approaches; however, to a large extent is constructed by the healthcare systems and structures which deliver healthcare. The following sections outline Australian and Tasmanian approaches to chronic conditions care and management, also providing an overview of the Australian healthcare system.

2.5.1 Australian approaches to healthcare and chronic conditions management

In Australia, healthcare is shared across federally funded ('Commonwealth'), state funded and (increasingly) local government funded agencies. Local government has more recently taken roles in health, particularly in rural areas, through general practice ownership and management, and preventative health roles such as seniors' health officers (see Shires Association of NSW & Baum 2004; Liaw & Kilpatrick 2008). Australian approaches to chronic conditions treatment and management can be generically grouped into three styles:

(a) primary health care (including care planning and multidisciplinary approaches)
(b) lifestyle (including health and wellbeing) type approaches and
(c) disease-specific approaches (including clinical guidelines and chronic conditions self-management).

This section looks at primary health care approaches (including Medicare, care planning, and multidisciplinary approaches), lifestyle approaches, and chronic conditions self-management; before looking at Tasmanian specific chronic conditions approaches.

(a) Primary Health Care (Medicare, care planning, multidisciplinary approach)

Medicare is the conduit for the bulk of Commonwealth healthcare responsibilities, and is a "universal health insurance model based on a progressive levy, [… which] provides free access to hospital care based on need, and free (for low income earners) and heavily subsidised access to primary medical care for all" (Baum 2008, p. 62). Medicare has a fee for service structure, whereby payments to health professionals are generated by numbers of service encounters and procedures or interventions (Swerissen & Taylor 2008), typically provision of medical services, pharmaceutical subsidies, and aged care packages. Funding via Medicare in Australia is historically medically focused, with relatively limited recent additions to the Medicare schedule for other professions doing community healthcare (midwives, general practice nurses, allied health professionals) (Williams, L 2005). Community nursing of veterans and nursing home care are also federally funded, although other community and hospital nursing services are state based. Wholesale national health reforms have been continually proposed by various federal governments between 2006 and 2015, alongside academic advocacy that "[t]he increasing prevalence of chronic disease is a driver of health system reform in most economically advanced nations" (Jeon et al. 2010, p. 66).

Considerable chronic conditions healthcare therefore presently takes place via federally funded primary healthcare routes: general practice, general practice nursing, and some allied health positions. These are generally driven via clinical guidelines and (in some cases) specific funding through the Medicare Benefits Schedule (MBS). Funding for primary health care generally specifies ways of working with people with chronic conditions (for example, multidisciplinary care approaches). In 2000, the More Allied Health Services (MAHS) program was created to address rural shortages of allied health professionals, alongside Enhanced Primary Care (EPC) packages:

> … to encourage linkages between allied health service providers and general practitioners […] for case conferences between a GP and at least two other health care providers (Liaw & Kilpatrick 2008, pp. 165-166).

The EPC were allocated Medicare Benefits Schedule item numbers, and therefore federal government payments, specifically directed at people with chronic conditions and "complex care needs" (Liaw & Kilpatrick 2008, p. 166). In 2005, these were replaced by Chronic Disease Management items; whilst other initiatives have included Practice Incentive Payments (PIP) to "promote continuity and quality of care", Service Incentives Payment (SIP) "focussing on specific diseases and associated care processes [such as diabetes cycle of care]", and Team Care Arrangements (TCA) for "multidisciplinary care planning" (Swerissen & Taylor 2008, pp. 77, 79).

The Chronic Disease Management Plan [CDMP] and GP Management Plan [GPMP] are specific item numbers within the Medicare Benefits Schedule, and aim to encourage multidisciplinary team-based chronic conditions healthcare. However, concerns have been expressed that "care planning has been of limited success", and to some extent propagated closed communication, duplication of services, and a "suspicion that financial reward, rather than true collaboration, was the main motivation" (Lawn et al. 2015, pp. 84, 88).

Primary health care takes the central role in screening and community-based chronic conditions management; however,

> primary health care services are divided between public and private sectors, are responsible to different levels of government and work under a variety of funding arrangements, with no overarching policy to provide a common frame of reference for their activities" (Powell Davies et al. 2009, p. 1).

Home-based nursing care, for example, is provided through Home and Community Care (HACC) packages, which were federally funded but state administered for over sixty-five year-olds (Department of Health [Australia] 2013). General Practice Tasmania[11] noted "the central role of general practice in the prevention, early detection and intervention and management of chronic conditions", and urged cross-government support "for planned, systematic, ongoing care, rather than acute episodic care that is fragmented across sectors" (GP Tasmania 2010b). Such advocacy highlights the current situation where healthcare (for all conditions) is provided and funded by local, state and national governments as well as by private business; and thus inherently involves multiple locations and systems.

Notwithstanding the amount of policy attention, "[t]he level of general management of chronic disease in accordance with recommended care is surprisingly low" (Swerissen & Taylor 2008, p. 76). Care planning is often proposed as part of the solution; for example in the Enhanced Primary Care program, where "[c]entral to the EPC initiative is a shift from reactive, episodic care to longitudinal structured and comprehensive care" (Martin & Peterson 2008, p. 162). While care planning[12] has existed as a formal part of nursing and allied health work (see Martin & Peterson 2008, p. 163), formal recognition and training for care planning within general practice and medicine is more recent. Despite biopsychosocial approaches being endorsed within medical training for a number of years (possibly approaching two decades for GPs), "chronic illness is managed by a significant proportion of GPs in a chronic physical disease or biomedical framework because that is the dominant model" (Martin & Peterson 2008, p. 162). Equally,

[11] which became Tasmania Medicare Local in 2011.

[12] A 'care plan' in chronic conditions management is ideally a "patient-centred, collaborative care plan, based on timely assessments and targeted to each client" (Larsen 2013a, p. 17).

whilst care plans "can be associated with improved processes and outcomes of care [… ,] the same literature indicates some ambivalence and ambiguity about the actual tasks of care planning [and] how best to implement care planning" (Martin & Peterson 2008, p. 163).

Encouraged by the Australian federal government via the Sharing Health Care Initiative (2000-2005), the involvement of multiple professionals and disciplines in patient-centred chronic conditions care has been considered "pivotal" (Cioffi et al. 2010, p. 62). An Australian systematic review by Dennis et al in 2007 concluded a multidisciplinary team approach to chronic conditions care improves both physiological disease measures and health professional adherence to disease management (Dennis et al. 2007). Yet clinician experience of multidisciplinary care is somewhat more equivocal. While healthcare professionals appreciate each other's strengths and contributions (for example, allied health professionals relying on nurses to do acute management and clarification of medical issues), sources of tension include under-staffing (particularly in rural areas, where missing or insufficient provision of certain disciplines such as dietician or occupational therapy means community nurses sometimes fill such roles), team cohesion, and "blurring and misunderstanding" of different roles (Cioffi et al. 2010, p. 67). Allied health professionals described "hav[ing] to fit in a bit" with general practice ways of working (Kirby, S et al. 2007), and it appears "uncommon for clinicians to discuss and agree on a plan of care" (Kirby, S et al. 2008).

Concerns are also expressed that general practitioners are "becoming coordinators and managers, not clinicians" (Best 2010), and equally that the MBS care plan items are "more of a paperwork process than genuinely sharing care" (Kirby, S et al. 2007). Allied health providers in particular describe restriction of Medicare subsidisation of their work to five visits (often shared across multiple allied health professionals) as inadequate, "due to the difficulties of addressing multiple and complex needs within prescribed timeframes" (Foster et al. 2009, p. 330). For example, a person with diabetes may be referred to a dietician, an optometrist, a podiatrist, and an exercise physiologist, however allowances are for five visits in total (across professions), when it is likely that multiple visits to all suggested allied health professions would be required to maintain good health and functioning over the course of a year or to make substantive lifestyle modifications. Calls continue for policies, which "fund and facilitate a real team approach that is in the best interests of patients — one that places greater emphasis on two-way communication rather than paper shuffling or gatekeeping." (Kirby, S et al. 2008; Foster et al. 2009; McDonald, J, Jayasuriya & Harris 2011; Johnston et al. 2012; see also Bacon & Borthwick 2013; Lawn et al. 2015). GP

Tasmania (amongst others) note the present fragmented, inefficient care (GP Tasmania 2010b) and complexity of navigating health services (Jeon et al. 2010, p. 66).

(b) Lifestyle Approaches and Clinical Guidelines

Lifestyle approaches are sometimes incorporated into primary care (eg 'lifestyle modification' such as weight management, where lifestyle is considered a contributory cause of or risk factor for disease (see Foreyt 2003; Hansen, EC & Easthope 2007; Egger, Binns & Rossner 2009; Speechly et al. 2010 ; Nilsen, Bakke & Gallefoss 2011; Christl et al. 2012). However health and wellbeing tactics (including fitness, general nutrition other than for those with specific diagnoses) are often considered outside the primary care remit, and therefore devolved to market forces, which often limit availability in rural and remote areas. Non-healthcare professionals (such as personal trainers) and non-professional healthcare workers (such as community development workers), local council fitness programs, disease-specific NGOs such as the Heart Foundation and MS Society, and commercial providers (such as health food stores, nutritional consultants, naturopaths within pharmacies) tend to operate (and be relied upon) in this preventative healthcare space.

Policy documents note

> …[e]very effort we can make to promote health and wellbeing and prevent chronic disease will not only help reduce the need for hospital care in the first place, but also costly care in all parts of the health system itself (Department of Health and Human Services [Tasmania] 2011a, p. 2).

Nevertheless, "governments of all persuasions have largely neglected the funding of real preventative action"(Egger, Binns & Rossner 2009), and disease-specific approaches predominate. Disease-specific approaches are often mediated by clinical guidelines, developed for various professions in acute and community contexts for many of the more common long-term conditions (see Commonwealth of Australia 2013). A 2010 study identified "nine times more guidelines than identified in 1993", "a sporadic one-off approach to guideline funding", and cited evidence that "half of such guidelines were out-dated within 5.8 years of being produced" (Buchan, HA et al. 2010). While evidence-based guidelines as part of decision support improve clinician adherence and patient disease measures (Dennis et al. 2007), for many health professionals "the relationship between lifestyle factors and people's health and even the meaning of lifestyle as a term remain ambiguous" (Hansen, EC & Easthope 2007). Nevertheless, with "60-70% of all primary health care visits in developed countries … for lifestyle-based diseases", lifestyle-based approaches remain "a means to address the health challenges posed by changes to lifestyle in the past three to four decades"(Egger, Binns & Rossner 2009). Lifestyle-based

approaches do, however, "require the patient to be more active in his or her own care" (Egger, Binns & Rossner 2009).

(c) Chronic Conditions Self-Management

Considerable interest has also been expressed in policy circles in variations of chronic conditions self-management (CCSM, also known as chronic disease self-management [CDSM]). Chronic conditions self-management focuses on "teaching patients to control their chronic illness more effectively", and includes group (eg Stanford model, see (Lorig 1994) and individual approaches (eg Flinders model (Battersby et al. 2008); Health Coaching (Gale 2010); and Motivational Interviewing (Mesters 2009). CCSM programs are often promoted as non-disease-specific, however more evidence is available from disease-specific cohorts (see (Townsend, Wyke & Hunt 2006). Some generic programs are run as disease-specific or disease-centric, for example, by attracting participants though a disease-specific non-government organisation (for example, the Multiple Sclerosis Society).

A systematic review of Australian experience of chronic disease management concluded "CDSM programs were effective at improving patient-level outcomes for hypertension, diabetes and heart disease" (Zwar et al. 2006, cited Katterl 2009); however were more successful when conducted in community-based settings and disease-specific groups (Zwar et al. 2006, pp. 41, 54) see also (Francis, CF, Feyer & Smith 2007). Dennis et al's systematic review also concluded that self-management support improved measures of disease, quality of life, health and functional status, service use and satisfaction (Dennis et al. 2007). However critics such as Harvey suggest that relying on self-management is inherently too focused on the individual, rather than on "the large social and economic determinants of wellbeing or … factors outside of the individual's direct sphere of influence and control." (Harvey & Docherty 2007). Limited rural and remote availability of both self-management programs and additional healthcare resources encouraged through such programs are also "significant issues" in rural and remote self-management of chronic conditions (Sav et al. 2015).

My research concurs with suggestions that self-management is "only one component of chronic disease care" (Jordan & Osborne 2007, p. 87); also with Harvey's suggestion that chronic conditions self-management generally appears to be "a means of improving quality of care for consumers rather than … to generate cost savings" (Harvey & Docherty 2007, p. 190). My research therefore focuses on existing clinician practice, where "both patient and clinician … work hard to achieve the goal of getting on with life" (Mol 2008, cited Greenhalgh 2009, p. 628)

without formally engaging in self-management; as the bulk of present chronic conditions healthcare.

2.5.2 Tasmanian Approaches to Chronic Conditions

The Tasmanian State Government is responsible for hospitals, management of community nursing, and public allied health provision (hospital and community). The Chronic Disease Action Framework for Tasmania 2009-2013 incorporates theories such as the Wagner's Chronic Care Model (see Section 2.4.2) and a health promotion framework (Department of Health and Human Services [Tasmania] 2009, pp. 56-57), and notes the need for a "coordinated and strategic approach to improve the prevention, detection and management of chronic disease in Tasmania" (Department of Health and Human Services [Tasmania] 2009, p. 6). A Chronic Disease Clinical Network was established in Tasmania in 2009, but discontinued in 2011 due to funding cuts (see Clinical Network Coordinator DHHS, personal [group] communication, 18-8-11).

Self-management support has been prominent in DHHS chronic conditions policy discussions, and a number of different approaches and trainings offered, trialled and variously utilised. Between 2006 and 2015, the DHHS has run staff training in Stanford (also known as 'Get The Most Out of Life' [GTMOOL]), Flinders, Health Coaching, and Motivational Interviewing. Patients in various parts of Tasmania have been offered the above, as well as hospital clinic-based programs for cardio-pulmonary rehabilitation and diabetes education, and locally developed self-management programs such as CENTR'd (Cameron-Tucker et al. 2009) [Hobart], Appetite for Change (Macey & ABC 2009) [north-west Tasmania], and Pathways to Health (Jessup et al. 2006; Walters, Cameron-Tucker, et al. 2012) [Huon Valley and Hobart].

Tasmanian experience of self-management programs is presently equivocal for both patients and healthcare professionals. Robinson et al (reporting on their pilot COPD project) are positive (Robinson, A. et al. 2008); however, Bell and Orpin suggest "rural health contexts present particular challenges for self-management education programs […] when transplanted to rural and remote communities without careful attention to specific barriers to self-management in those communities" (Bell & Orpin 2006). Bell and Orpin perceive "access to transport", "lack of education, age-related physical frailty, and poverty" as significant barriers to self-management in some rural, regional and remote areas, but noted that (unusually) men who were enrolled in one particular course were more likely than women to complete (Stanford unmodified, August 2002-September 2003) (Bell & Orpin 2006). In particular, Bell and Orpin suggest that local advocates can assist with community development aspects (longer term sustainability of self-management

programs) and with targeting those most in need, rather than those "already relatively well placed" (Bell & Orpin 2006).

A small internal DHHS study into successful Stanford leaders noted environmental (middle and upper management) support was crucial to embedding Stanford programs and enabling availability for clinicians to lead the program (Spinaze & Griffiths 2012), heightened by sectorial pressures to compete with the "acute 'medical model'" and corresponding funding allocations (Griffiths 2012). However the reach of self-management training across DHHS clinical staff is difficult to assess, in particular given regular departmental restructures (see Department of Health and Human Services [Tasmania] 2011b; Hidding 2015). DHHS staff estimate that between 2007 and 2011 nearly 700 employees attended various self-management training opportunities (Flinders, Stanford, Motivational Interviewing, Health Coaching, CDSM forum/s, and CDSM-related systems and organisational change workshops; with online packages also available) (Griffiths, personal communication 14-11-13). Self-management support competence within Tasmanian general practitioners is unknown; however, research into general practice nurses already involved in chronic disease management observed that "[self-management] training enhanced their understanding and skills of self-management approaches and increased the focus on patient partnership, prioritising patients' choices and achievability" (Walters, Courtney-Pratt, et al. 2012).

Walters et al equally note "there are significant system barriers [to self-management support delivery in GP contexts] that need to be addressed through funding models and organisational change" (Walters, Courtney-Pratt, et al. 2012). With limited self-management uptake and delivery, research into chronic conditions healthcare needs to consider approaches other than self-management support activities.

2.6 Chronic Conditions Healthcare: A Working Definition

The final section of this chapter relates to a working definition of 'chronic conditions healthcare', as derived from the literature and used to guide the subsequent research fieldwork.

It is important to reiterate that the bulk of chronic conditions healthcare work is done by patients, rather than by healthcare professionals. In a culture where unpaid caring work (eg self-care, parenting, support of disabled family members, fostering, support of elderly) is generally de-prioritised in discussions of work, I accept it is somewhat divisive to focus on healthcare work done by professionals. I by no means intend to negate the expertise of patients and unpaid carers;

rather to shine light upon a type of professional healthcare work which has not to date had sufficient focus.

I also use 'healthcare', rather than 'care', as whilst much nursing literature uses the term 'care' to indicate normal nursing work, allied health and medical literature generally does not. I believe the phrase 'chronic conditions healthcare' encompasses the work of all these three major healthcare sub-disciplines (medical, nursing, and allied health), and helps focus attention on the experiences of clinicians, rather than those of patients and (familial rather than paid) carers. While the chronic conditions healthcare work done by people with long-term conditions and their carers is not to be denied or minimized, this research is concerned with the healthcare work of paid healthcare professionals. This thesis focuses on paid clinicians' experiences of chronic conditions healthcare, so paid employment forms the basis of the definition.

Equally, the phrase 'chronic conditions healthcare' is my own, and not one within current healthcare professional or academic lexicon. Appropriate terminology will be determined repeatedly over the next few decades - by academic, advocate and public consensus - and 'longterm conditions healthcare' may well be more appropriate. Whilst I believe 'longterm conditions' is a more accurate term to use (less jargonistic, and potentially less threatening to people experiencing longterm conditions), for the purposes of my research it was important to use terminology familiar to Australian clinicians. The findings of this research, as a snapshot of early twenty-first century chronic conditions healthcare, will stand, irrespective of terminological shifts.

Hence, for the purposes of this thesis, 'chronic conditions healthcare' is defined as 'paid work done by healthcare professionals, generated by individuals or populations with one or more longterm conditions'. This is a definition which was constructed independently of participant input, prior to fieldwork commencement (participant definitions will be discussed in Chapter Five). Similarly, any definition of 'chronic conditions healthcare' rests upon a definition of 'chronic conditions', and early in my research, I defined a chronic condition as "any physical or mental illness, disease or disability, which affects long-term health" (see Appendix 1A). Chronic conditions healthcare thus operates across primary, secondary and tertiary healthcare, and includes any clinical, interpersonal, inter-professional or administrative work done by health professionals; prompted by individuals, families or social groups with one or more chronic conditions.

2.7 Summary

In this chapter I explored chronicity as a concept, and reviewed predominant literature about chronicity in ill-health. In an age of patient-centred care, theoretical perspectives on chronicity provide different ways to encapsulate patient experience, and to conceptualise different ways that healthcare systems can address long-term conditions. I therefore examined the experience of chronic conditions (patient perspective 'chronic illness' literature, health professional experience of being a patient, rural chronic illness experience, and the particular and changing nature of patienthood due to the rise in chronic conditions). I then explored dominant theoretical constructions: the chronic illness trajectory framework, Wagner's six factor Chronic Conditions Model, and chronic disease self-management theories. Current types of chronic conditions practice (Australian and Tasmanian management approaches) were outlined, in order to provide theoretical and policy approaches for contrast with the actualities of experience reported later in this thesis. Finally, a working definition of 'chronic conditions healthcare', for the purposes of my research and this thesis, was developed.

The dominant sense of the literature is one of rapidly changing times, and to some extent, a loss of clinician voice amidst policy debates, academic discourse, and patient emancipation:

> As valuable as these studies might be, something crucial is missing. My view is that to really understand a human experience, it must be appreciated from the subjective point of view of the person undergoing it. (Karp 1996, p. 11)

Clinicians are at the coalface (as discussed in Chapter Three), but are not the sole or even the dominant voice of authority in patient care. It appears that there is systemic bias against holistic understandings of and approaches to chronic conditions, and thus away from *modus operandi* which accommodate the changed role of the patient in chronic conditions healthcare. There is a developing understanding of the biological manifestations of chronic conditions, and to some extent the experience of people who have chronic conditions. However, where the work of improving health status is explicitly shared between people with long-term conditions, their healthcare providers, and healthcare systems, the experiences of such clinicians are also important. The demographics and contexts surrounding clinicians are further explored in Chapter Three.

3 Healthcare Workers

3.1 Introduction

To better understand chronic conditions healthcare, it is important to understand the healthcare professionals that do chronic conditions healthcare. Chapter Three reviews literature that documents who it is who is doing chronic conditions healthcare, and demographic and cultural factors experienced by that cohort. Worldwide, there are some understandings of systemic and contextual factors which influence the presence, absence and effectiveness of healthcare. However there is limited understanding of the contextual factors which construct healthcare professionals' capacity to engage in chronic conditions healthcare. In Chapter Three I explore health professional work experience in healthcare generally and in rural contexts, and therefore (through peripheral views from research focused in other areas) within chronic conditions healthcare itself.

In Chapter Three I demonstrate there is insufficient evidence of the experience and understandings of healthcare professionals of what it is to do chronic conditions healthcare, although there is some understanding of the primary healthcare professionals who presently do such work. Understanding how demographic and sociocultural imperatives may affect chronic conditions healthcare, is crucial to answering the research question: to achieving an understanding of what it is like to actually 'do' chronic conditions healthcare.

3.2 Who are the people doing chronic conditions healthcare?

When this research commenced, there were around 450 000 paid health professionals (Productivity Commission of Australia 2005, p. vi). More recent figures suggest that more than half (62.7%) are in nursing occupations, medical professionals comprise 17.2%, dental practitioners 3.5% and allied health professionals 16.6% (Australian Institute of Health and Welfare 2012, p. 502) (where allied health includes pharmacy and paramedic work). In Tasmania, there were 605 GPs in 152 practices across Tasmania (Tasmania Medicare Local Ltd 2012, p. 4), and 11 501 (9290 FTE) DHHS employees for a similar period (Department of Health and Human Services [Tasmania] 2013a, p. 17). Significantly, health worker shortages are significant in outer metropolitan, rural, remote and indigenous communities, despite the health workforce "growing at nearly double the rate of population" (Productivity Commission of Australia 2005, p. vii). However, "[o]utside of metropolitan areas the concept of health workforce can be much

broader, and boundaries between health, community services, schools, police and correctional services, local government and children's services are often blurred" (Health Workforce Australia 2011).

Reliance on overseas-trained healthcare professionals in Australia is clear (see Durey 2005; Bourke, Coffin, et al. 2010). Overseas-trained workers comprise 25% of the medical workforce in general (Productivity Commission of Australia 2005), and 5% more in Tasmania than in the GP workforce as a whole in Australia (Gartlan et al. 2006; Tasmania Medicare Local Ltd 2012). Within the Australian rural health workforce, nurses again represent the greatest proportion of the workforce at 65%, a percentage which "increases markedly with remoteness" (Francis, K 2006).

The health and wellbeing of the potential research population is of interest, as the basic health or otherwise of clinicians is crucial to their capacity to engage in any healthcare. However specific data on Tasmanian healthcare workers is difficult to find. One in eight Tasmanian workers are employed in the State Service (Teale & Venn 2012), and evidence of staff health within the state service provides a window: the "majority of staff are not getting enough physical activity outside of the workplace, and many staff spend six hours or more sitting in a day." (Healthy@Work, Menzies Research Institute [Tasmania] & Tasmanian Government 2010, p. 2). Equally worryingly, "half of the state service is overweight or obese and most are not eating sufficient amounts of fruit and vegetables." (Healthy@Work, Menzies Research Institute [Tasmania] & Tasmanian Government 2010, p. 2). Healthcare workers within Tasmania are unlikely to vary widely from these overall statistics. Certain healthcare professions are also at higher risk than general population for mental illness, prescription medication abuse and stress-related problems (for doctors, see Schattner, Davidson & Serry 2004; Elliot, Tan & Norris 2010), (for nurses, see Rose, J & Glass 2010; Huntington et al. 2011), (for social workers, see Beddoe, Davys & Adamson 2011). Healthcare professional workforces are also generally considered to be ageing, as discussed below.

3.2.1 Healthcare worker demographics are changing

The demographics of the health workforce are clearly shifting, with two predominant issues emerging in the latter half of the twentieth century. The first is an ageing workforce in general as well as in healthcare particularly (Productivity Commission of Australia 2005, p. 340; Schofield, D & Beard 2005), and the second is the 'feminisation' of traditionally male dominated professions such as medicine, dentistry and pharmacy. The sections below examine ageing of the healthcare

workforce, and then gender of healthcare workers. These changing demographic indicators are further explored in examining shifting work preferences and roles.

3.2.2 Ageing Healthcare Workforce

The health workforce in 2010 "was older compared with the overall workforce", with "one-quarter of generalist medical practitioners aged 55 or older" (compared with "about one-sixth in 2005" (Australian Institute of Health and Welfare 2012, p. 496). Proportions of older social workers and nurses had also increased, although the proportion of older pharmacists decreased from 34% to 17% (Australian Institute of Health and Welfare 2012, p. 496). Whilst healthcare professions are generally considered to be ageing (and this will be further discussed below), Services for Australian Rural and Remote Allied Health (SARRAH) reports that the outer regional allied health Tasmanian workforce is especially affected; particularly audiologists, dietitians, medical imaging, physiotherapy, psychology, public pharmacy and social work (Services for Australian Rural and Remote Allied Health [SARRAH], Lowe & O'Kane 2004). Schofield and Beard note:

> GPs already have retirement patterns that conform to the Treasury ideal — gradual retirement and working beyond traditional retirement age as a solution to an emerging labour force shortage and to fund the future health costs of an ageing population. However, there are more than 200 000 nurses in a profession from which early retirement is typical (Schofield, D & Beard 2005, p. 83).

Schofield and Beard emphasise the need to address nursing early retirement patterns, and described tactics such as less physically demanding jobs (for example, general practice nursing rather than hospital work), more flexible shift work arrangements, and enabling of job satisfaction, as crucial to employee retention. Elsewhere, however, Schofield and others note that "rural nurses retired significantly later than city nurses" (Schofield, D et al. 2006, p. 3), so it is possible the differences between rural and urban nursing retirement patterns are not well documented. Tasmanian medical workforce participation has remained relatively static overall; however "the most significant change" is "the trend towards increasing workforce participation in part-time hours", increasing from 13.7% to 20.2% of the workforce between 2005 and 2012 (Tasmania Medicare Local Ltd 2012, p. 13). Given an ageing workforce, increasing part-time work participation, and with baby boomer healthcare professionals reaching retirement age, there are real concerns around future labour force shortages.

3.2.3 Gender in Healthcare Workforces

The Australian healthcare workforce has traditionally been predominantly female (75% in 2010), with nursing currently 91% female, generalist medicine 44% and allied health 64% (Australian Institute of Health and Welfare 2012, pp. 498-499). Tasmania's healthcare worker demographics

are no exception, with 80% of DHHS clinical staff female (Stephanie Haines-Ferguson, DHHS statistician, pers. comm. 9 September 2012). Medicine has been less female-dominated than other health professions in the past; however the 2012 Census of Tasmanian GPs notes "the trend of increasing feminisation of the workforce continues, with the increase in numbers of female GPs since 2005 at over three times the rate of increase of male GPs" (Tasmania Medicare Local Ltd 2012, p. 4). Female GP full-time-equivalent workforce participation overall in Tasmania increased by 5.7% between 2005 and 2012 (Tasmania Medicare Local Ltd 2012, p. 15). Tasmania Medicare Local also notes that "at 44% of the GP workforce, Tasmania's female GPs continue to exceed the national proportion of female PGs by 3.5%" (Tasmania Medicare Local Ltd 2012, p. 4).

Correlations between being female and reduced work hours and/or increased part-time work engagement are clear: "Women in the workforce… on average, … work fewer paid hours per week than their male counterparts" (Australian Institute of Health and Welfare 2012, p. 493). Remote healthcare has possibly always been an exception (Bardenhagen 2004), with both female and male workforce participation increasing with increasing rurality and/or remoteness (Tasmania Medicare Local Ltd 2012, p. 4, see also McGrail et al. 2012). Remote nurses generally work alone or in small teams (Project Organising Committee of the Nursing Organisations of the NRHA 2002; Mills, Birks & Hegney 2010), and the highest medical fulltime female workforce participation occurs in the most rural region of Tasmania (north-west with 48.7%), with the lowest in the more urbanised south (35.2%) (Tasmania Medicare Local Ltd 2012, p. 6). At the same time, male workforce participation rates (hours per week) in some professions is also declining (Tolhurst & Stewart 2004; Productivity Commission of Australia 2005), and GP Tasmania noted that the most pronounced shift in pattern of work participation within their 2010 Census was an increase from 7% (2005) to 15% (2010) in "males practicing part-time hours of 2 days or less" (GP Tasmania 2010a). Such evidence supports the Productivity Commission proposition that,

> … the greater feminisation of the medical workforce has not so far been the major driver of the decline in average hours worked. The decrease in average hours worked by male medical practitioners has been much more important. (Productivity Commission of Australia 2005).

It is thus possible that generational change in work-gender-identity amongst men is as much at issue as gender-specific work engagement patterns.

Such shifts imply that the working patterns of females and males across health disciplines continue to have repercussions for health workforce planning. Gender implications need also be considered within chronic conditions healthcare: who will be available to do chronic conditions

healthcare, and within what personal constraints? Taken as a whole, the literature suggests that health professionals are looking for particular types of work, which may impact on how chronic conditions healthcare gets done. The following section looks at the shifting of workforce preferences, in line with gender roles more broadly.

3.2.4 Shifting Workforce Preferences

The increasing female population within workforces, alongside ageing workforces, continue to heighten the effects of different intergenerational workforce preferences. Generation X and Y doctors are "known to have a different perception regarding workload, lifestyle and the support required to practise" (Laurence et al. 2010, see also Tolhurst & Stewart 2004). The reduction in the "'super doc' rhetoric" is associated with increased retention of female GPs in rural areas (Wainer 2004a), with "morale… implicated in retention because contented doctors stay in rural practice longer" (Schofield, D et al. 2006, p. 6). The concerns of some older doctors regarding younger doctors' work hour preferences play out in rural as well as urban settings, with rural Generation X GPs "no more likely to work long hours than their city peers" (Schofield, D et al. 2006, p. 3). It is also possible that rural Baby Boomer clinicians are looking for different opportunities towards the ends of their careers, with "relocation to urban or overseas areas… [constituting] 36% to 49%" of attrition (Rural Workforce Agency of Victoria, cited (Schofield, D et al. 2006, p. 5).

Nursing appears to function differently, with rural nurses "unlikely to leave employment for alternative careers" (Schofield, D et al. 2006, p. 7), ie possibly more stable geographically than doctors. However, both Baby Boomer and younger clinicians tend to have children later in life than the general population, and "increased overall life expectancy means they may now also have elderly relatives to care for" (Schofield, D et al. 2006, p. 6). In the United Kingdom, "one-third of nurses in the 50+ age group… report caring responsibilities that impact on their work engagement" (Buchan, J 1999); and recent Australian research suggests that "women who combine care of children with other care responsibilities – the 'sandwich' generation – have worse work-life outcomes than any other categories" (Skinner, Hutchinson & Pocock 2012, p. 9). In Tasmania, 67% of DHHS staff (male and female) are part-time (Haines-Ferguson & DHHS 2011), and while no specific evidence is available, it is possible that the 'care sandwich' (responsibility for both ageing relatives and children/adolescents) partially drives part-time work engagement in this cohort.

Equally, healthcare professionals are part of "an increasingly mobile and transitory workforce" (Kilpatrick et al. 2011, p. 181), and may vote with their feet when work-life balance becomes unmanageable. Research into community mental health nurses notes the difficulty of "exaggerating the unity and stasis of a nursing identity", and the necessity of conceptualising the community nurse role as dynamic and responsive to shifts in career path, attitude to work, "the perpetually changing impact" of family, and sense of self (Majomi, Brown & Crawford 2003, pp. 528, 535). However Majomi et al also note that "even when staff are apparently coping with their roles at work and home, difficulties may be building up which could lead to a sudden period of absenteeism or disillusionment" (Majomi, Brown & Crawford 2003, p. 527).

The Centre for Research on Families and Relationships notes "work-life balance is dependent on a mixture of state policies, individual circumstances and cultural factors" and will not respond to any one particular policy tactic (Centre for Research on Families and Relationships 2004). Nevertheless, Todd et al note that work-life balance is now considered a problem for Australian public sector management, although largely managed at individual more than policy levels (Todd & Binns 2011). Eckermann and Howard consider the problem exacerbated in rural areas, citing Rural Doctors of Australia figures which suggest 40% of doctors work more than 60 hours per week (compared with 26% of metropolitan) (Eckermann & Howard 2008). Eckersley notes,

> … [in an environment of lower job security, lower loyalty and average tenure], happiness at work is likely to be the glue that retains and motivates the high-quality employees of the future (Fisher 2010) (p404).

To some extent, health professional roles and tactics are changing in response to the conditions and demographics discussed above. While health professional identities are individual, reflexive and context dependent specific to particular kinds of rural experiences (Spinaze 2009a), equally clinicians adopt particular tactics which aid their "thriving, not just surviving, in emotionally demanding fields of practice" (Wendt, Tuckey & Prosser 2011). As well as changing environmental conditions and shifting patient and professional demographics, "life experiences, ideologies, beliefs, values and other life resources" inform and influence healthcare professional work (Wendt, Tuckey & Prosser 2011).

3.3 Experiences of Healthcare Work

Healthcare professionals clearly shape certain aspects of patient experience of chronicity and chronic conditions; however, as I demonstrate, their own experiences and understandings of doing this kind of work are not well conceptualised or understood. Experiential literature in health is generally focused on patient experience, even where the clinician is in focus (for

example, the doctor-patient relationship as viewed from the perspective of the patient, see Colavita 2004; Acker 2008).

In the absence of literature which specifically examines the experience of chronic conditions healthcare, this section of the literature review explores broader clinician experiences of healthcare work. I divide health professional experience literature into three categories:

- general healthcare work experience,
- rural work experience, and
- healthcare professionals' views of chronic conditions healthcare from within other literature (generally patient-perspective literature).

I then discuss some seminal movements identified in this literature.

3.3.1 General Healthcare Experience literature

The experience of doing healthcare work has been studied from multiple angles, within profession-specific (medical, nursing and allied health), biomedical, and social science literatures (including organisational, sociological, anthropological and cultural geography disciplines). There is documentation of health professionals' experience of specific kinds of practice, generally in the form of 'professional identity' narratives. In general, however, and in long-term condition management in particular, there has been considerable complexity and change within healthcare professions: "What we can do for patients has changed so much over the past twenty years that it often bears little relation to what health professionals were taught at university" (Robinson, BG & Brooks 2012).

Primary healthcare professionals inherently experience a number of roles within their specific professional role, and the complexity of incorporating and managing these multiple roles is crucial to their experience of work. For example, Benner includes 31 competencies in her detailed exploration of nursing work: some directly relate to chronic conditions healthcare, including:

- Teaching-Coaching Function,
- Diagnostic and Monitoring Function,
- Administering and Monitoring Therapeutic Interventions and Regimes,
- Monitoring and Ensuring the Quality of Health Care Practices, and
- Organization and Work-Role Competencies (Benner 2001 [1984]).

Such competencies are currently incorporated into concepts such as 'coordinated care', 'care management', 'chronic disease management'; however Ehrlich et al consider that these "[rely]

heavily on complicated concepts such as partnerships, networking, collaboration, knowledge transfer, person-centred practice and self-management support, which are poorly articulated and often not translated into practice." (Erlich et al. 2009). While "nurses have traditionally provided the majority of primary health care services in rural and remote Australia" (Francis, K 2006); Keleher et al contend they are

> … employed in the primary health care and community sectors with little specific preparation or education. Acute care nursing is based on competencies and evidence-based practice, but these frameworks are missing in primary and community nursing. Competencies and career pathways differ from acute nursing but are given little, if any, attention in undergraduate programs (Keleher et al. 2007a, p. 1).

Brookes et al concur, noting concerns about "conflicting role expectations between different facets of the health care system" (Brookes et al. 2004, p. 195). They explore the role of community nurse, observing that in the acute care sector,

> … the title 'intensive care unit nurse' has a clear role definition and most health care professionals understand what the role involves, [whereas] a community nurse in Australia may be otherwise known as a 'community nurse', a 'district nurse', a 'home nurse', a 'generalist community nurse', 'a 'community health nurse', a 'primary health care nurse', or a 'domiciliary nurse'. The multiple terminologies used for job titles contribute to the confusion and lack of understanding about the role. (Brookes et al. 2004, p. 199).

They also note that specialisation within community nursing might crowd out care "that focuses on not only the individual but the family and community", replacing it with "care delivered to the patient within an acute care framework as practiced by nurses with a specialty focused orientation" (for example in congestive heart failure, stoma care, continence care, etc) (Brookes et al. 2004) p204. Increased specialisation within community nurse roles has implications for who does chronic conditions related work, and how, particularly in non-hospital (primary and community healthcare) sectors. For example, if patients are allocated to disease-specific specialists, who will specialise in those with multiple conditions, or with conditions without a particular specialist? How will the quality of such practice be assessed?

More directly experiential literature includes that by Henriksen (Henriksen & Hansen 2004) and Gass (Gass 2004). I highlight these authors, as they place the personal perspectives of healthcare professionals about their experience of doing healthcare work at the centre of their articles: Henriksen and Hansen in terms of practitioner reflexivity and thought processes surrounding prescribing, and Gass in terms of day-to-day, long-term care work. The former look at general practitioners' self-perception in relation to pharmaceutical prescribing, whilst the second is an experiential account of being a professional carer in a residential aged care facility. Henriksen and Hansen demonstrate that "self-perception is fundamental to how GPs prescribe medicines", and

note that further research should "include considerations of the GPs' self-perception and facilitate autonomous self-development" (Henriksen & Hansen 2004, p. 47).

Gass, while not a 'professional' in the sociological sense (as a low-paid carer with low status and limited autonomy within the healthcare system), nevertheless provides a rare and detailed examination and personal perspective, on the experience of working with the same people for extended periods. He summarises concern with present healthcare funding arrangements by pointing out that "[i]ll-health directs our actions, charts our success, and guarantees our pay-checks" (Gass 2004); suggesting that present healthcare structures appear to be illness care systems rather than healthcare systems.

Such texts satisfy, to some extent, Kleinman's call for accounts which prioritise "the internal, felt experience of doctoring [and nursing, and doing allied health work], the story of what it is like" (Kleinman 1998, p. 210). However there is no detailed examination of what it is like to do chronic conditions healthcare as a healthcare professional. This thesis, in addition to accounts such as Gass's, addresses Henriksen and Hansen's call to explore clinician self-perception, whilst reconnoitring the relatively unexplored terrain of experience of healthcare professional work.

3.3.2 Rural Healthcare Experience literature

Rural healthcare work experience forms a particular subset of international healthcare work experience. From part-fiction, part-autobiography *fin de siècle* accounts (eg Sarah Orne Jewett 1884, Bulgakov 1925), through to the 1969 photo-essay of Berger and Mohr (Berger & Mohr 1969) and on-going Royal Flying Doctor publications, the experiences of rural and remote clinicians have always been of intense interest to the general public. However, most accounts are more literary than academic. Australian exceptions include (Wainer 2001; Ozolins, Greenwood & Beilby 2004) and (Ward 1999), which focus specifically on female rural medical experience. There is also a "largely fictional [text] … based on the author's real life experiences" (Carter 2010), and more academic, although still autobiographical, accounts of rural experience for medical education purposes (eg Hays 2002). Rural and remote nursing, also known in Australia as 'bush nursing', has produced multiple academic accounts (Lee & Winters 2006; Montour et al. 2009; Rosenthal 2010; Scharff 2010; Troyer & Lee 2010; McConnell-Henry 2012). However rural allied health discussions are relatively limited, other than in one multidisciplinary study by Chipp (Chipp et al. 2011). Remote Australian social work is scrutinized by Krieg-Mayer (Krieg-Mayer 2001), and Allan et al examine "contextual keys that shape … health workers' experiences in rural areas" through interviews with pharmacists and social workers:

> Pharmacist: "You have to face your mistakes in the street. That's the hardest thing and the main difference between rural and city work" (Allan, Ball & Alston 2008, p. 6).

Allied health in general has considerably less available research, and apart from those mentioned above, is generally descriptive statistics.

Specifically Tasmanian accounts of healthcare include Wildencamp's and Madill's medical autobiographies (Wildencamp 1998; Madill 2005), and Bardenhagen's nursing history (Bardenhagen 2004). Tasmanian allied health practitioners at this stage appear to be solely represented by survey data (Services for Australian Rural and Remote Allied Health [SARRAH], Lowe & O'Kane 2004).

What such accounts have in common are colourful anecdotes, and a perception that rural practice involves particular relationships, contextual intricacies and the tailoring of clinical approaches to allow for more difficult or delayed access to more specialised services. What is theoretically described as the rural 'specialist generalist' clinical role is also often highlighted (Wakeford 1999; Council of Remote Area Nurses Australia [CRANA] 2001; McKenna, Keeney & Bradley 2003; Brookes et al. 2004; Wainer 2004b; Pashen et al. 2007; Williams, E, D'Amore & McMeeken 2007; Bourke, Coffin, et al. 2010; Rosenthal 2010; Troyer & Lee 2010), as are perceptions of 'distinct rural ethics' (Crowden 2008), and social (personal) as well as professional pressures (Allan, Ball & Alston 2008). Less 'dramatic' stories, such as those occasioned by ongoing chronic conditions healthcare, appear infrequently or are omitted altogether. Memorable patient deaths are recounted, but not the years of regular monitoring and 'medication tweaking' visits which would be clinically likely prior to some of these deaths. Births, accidents and acute exacerbations feature highly; however, slow and steady frequent interactions and small incremental 'wins' are lacking. What Kleinman describes, perhaps inaccurately, as the "difficult and burdensome" "care of the chronically ill" (Kleinman 1998, p. 224) is largely absent in anecdotal accounts, as well as in research. My research seeks to fill this gap.

Identity work, the individual psychological work of understanding what it is to be simultaneously human and a clinician, is also rarely highlighted within clinician and academic accounts of healthcare work experience. Academic discourse (Eley, Young & Shrapnel 2008; Eley, Young & Przybeck 2009) examines whether there is such a thing as 'a rural temperament', and nursing identity also gets more broadly if not thoroughly or conclusively explored (eg Crawford, Brown & Majomi 2008; Van Galen 2013), regarding professional identity). Occasionally writers also foray into factors more basic to shaping of experience, depicting demographic factors such as

gender and race. Brown (2009) and O'Lynn (2010) explore male nursing, and White (2011) recounts his experience of becoming a surgeon as an African American.

However, most academic literature aligns with and contributes to the perception of healthcare professional work as separate from day-to-day existence. Some rurally-focused articles provide brief exceptions, in occasional acknowledgement of the porous nature of professional and personal boundaries within smaller communities. However the overriding impression is one of objective, rational actors dispensing evidence-based practice. This thesis seeks to fill the gap, by investigating clinician experience of one particular area of clinical work, and its intersections with personal as well as professional experience. In examining the experience of doing chronic conditions healthcare, and the intersections between personal as well as professional experience, this research may provide additional windows into other kinds of healthcare.

3.3.3 Chronic Conditions Healthcare Experience literature

My extensive research has not uncovered a systematic, developed body of literature regarding the experience of doing chronic conditions healthcare (current or past). I concluded both that (1) such literature is rare, and (2) that what there is, is difficult to find. This appears in stark contrast to other fields in healthcare; such as experiences of midwifery, palliative care, surgery, emergency, and rural healthcare. What work I did find was concealed within different literatures, fragmented and somewhat piecemeal, requiring the reader to synthesize multiple perspectives to 'join the dots'. The following are mostly synthesized from health sociology, nursing and anthropological literature.

'Caring work' has been explored within nursing research in some detail. Several twentieth century health sociologists contend that the healthcare system has historically evolved to segregate 'curative work' as "largely men's work", with women delegated the 'caring work' with "relatively lower status, lower … financial rewards and commonly much less control over work patterns and resources" (Jones 1994, p. 281). Further, they consider caring work in health as:

> …in some ways reflects and reproduces in the public domain the work of cleaning, cooking, housekeeping, nursing and nurturing performed as unpaid domestic labour in the private domain. […]. [In contrast,] Curative work (as performed by medical personnel) is far removed from domestic labour; … [and sited] away from the home. (Jones 1994, pp. 281-282).

Notions of 'caring' and 'emotional labour' (Hochschild 1983), are thus considerably discussed in nursing theory and gender studies, but neglected in general medical literature (an exception is the GP blog Tomlinson 2013). Benner suggests "caring is devalued and the primacy of care is culturally invisible because caring is associated with 'women's work', and women's work is

devalued and most often unpaid" (Benner & Wrubel 1989, p. 368). It is possible that particular kinds of chronic conditions healthcare (monitoring, medication management, for example), which are largely sited in community healthcare settings and associated with lesser status clinicians (general practitioners, allied health professionals and community and practice nurses; rather than physician specialists and clinical nurse consultants) are similarly invisible.

Concerns around commodification of "the healer's art" (Kleinman 1998, p. 222), have been expressed. Kleinman considers that "bureaucratic and legal constraints […] convert the role of healer into that of technician" (Kleinman 1998, p. 223), echoed by MacBride-Stewart (2012) in describing the 'new professionalism era' of general practice. MacBride-Stewart suggests that "commodification, compression and colonisation" processes provide a framework for exploring doctoring, yet that "when work is experienced as pressured, there is a risk that health professionals lose sight of nurturing relationship and focus their attention on the administrative and technical aspects" (MacBride-Stewart 2012). In one of the few studies of allied health experience of chronic conditions healthcare, Foster et al highlight similar difficulties, for health professionals given financial limitations to scope of practice (Foster et al. 2009). In Foster's allied health study, the nursing 'virtue script' (Gordon & Nelson 2006, p. 86) appears operational, with one research subject describing participating in Enhanced Primary Care plans as "like charity work", and another stating that there are:

> … some people who have these terrible problems who need your help who can't afford it, and the government is only paying a certain amount so you feel in a way that it's a moral obligation that you have to do your little bit. [Quoted in (Foster et al. 2009) p328].

Where chronic conditions healthcare is perceived as 'charity work', it is possible that it may be treated as an optional extra, or that moral value judgements ('is this case / person's concern valid? care-worthy?') may come into play. This research seeks to explore such concerns.

Rose and Glass found that there was "a pervasive interconnectedness between the participants' emotional work, emotional wellbeing and professional practice" (Rose, J & Glass 2010, p. 1408), implying that financial constraints on professional practice create additional emotional work. McPherson and Armstrong also support such interconnectedness, noting that where treatments fail, primary care clinicians (in this case GPs) construct frameworks which "imply a treatment worked only when the psychosocial conditions were right" (p1139), potentially leading to loss of empathy, and somewhat ad hoc prescription of social interventions, where biomedical attempts were unsuccessful (McPherson & Armstrong 2009). Even as biomedical explanations were proffered, "GPs drew upon lay labels and notions in the absence of medical ones that could work

for them" (McPherson & Armstrong 2009). Such brief glimpses into the lifeworlds of people doing chronic conditions healthcare highlight what Kleinman describes as a lack of ethnography of the experience of care or 'voice of the healer': "what the [clinician] feels is most at stake - what is most relevant to practice – slips through our crude analytical grids" (Kleinman 1998, p. 210). My research attempts to address this gap.

Other literature discusses the role of the clinician from the perspective of patient chronic condition experience. For example, Thorne outlines the position of healthcare professionals in the chronic conditions journey for patient participants in her Canadian patient-centred study:

> Health care professionals clearly hold the weight of authority in judging the merits of people's health complaints, determining a diagnosis and a course of treatment, and controlling access to precious health-related resources. Their actions and attitudes play an enormous part in determining the degree of distress that patients and families will have in the course of their chronic illness experience. […] [T]he calibre of health care relationships is central to the quality of health care (Thorne 1993, pp. 81-82).

Thorne also describes the physician (in Canada, a family physician is equivalent to the Australian general practitioner) as "most often the pivotal figure from the patient's and the family's perspective": due to the physician's positions as first point of contact with the health system, diagnosis and decision-making authority, and as senior within the health team (Thorne 1993, p. 82). Her informants describe "an ongoing relationship with a health care professional [as] especially important in chronic illness", with "the primary value of such long-term relationships [as] having someone to talk to" (Thorne 1993, p. 82). While this emphasizes the importance of continuity of care for chronic conditions healthcare, other literature emphasizes appropriate handover procedures, electronic records, and other ways of enabling continuity of care other than via a specific provider. Thorne notes that necessary validation of chronic illness experience could be provided by healthcare professionals of various disciplines: "Sometimes you don't even need problem solving, you just need to have somebody hear you and understand" (Thorne 1993, p. 83). The discipline of the healthcare professional providing that support did not appear to be strongly relevant (although there was a distinct suggestion that nurses were more inclined, and/or more available, to give this kind of care). A listening and hearing style of engagement with patients, alongside continuity for sometimes lifetime journeys, were clearly very important to her cohort.

An earlier work of Thorne's, whilst again prioritising the then rarer patient perspectives, can also be read as an exploration of clinician-patient relationships within chronic illness. 'Constructive non-compliance', rather than the traditional compliance, was considered typical of patients and

family members who were part of a three-year study into the changing nature of relationships between chronically ill patients and their clinicians. Thorne describes movements through stages of 'naïve trust', 'disenchantment' and 'guarded alliance', with the final stage of 'guarded alliance' relationships (varying from 'hero worship', 'resignation', and 'consumerism' through to 'team-playing') (Thorne 1990). Whilst this typology describes patient attitudes towards health professionals, it equally delineates some of the expectations health professionals may have of patients: that they should slot into the above roles or stages. More recently, McDonald et al note that professional identities are as dependent on patient identities as vice versa, and that, just as a patient who takes a more traditional 'sick role' engenders a more directive response, an empowered patient necessitates a partnership approach (McDonald, R, Rogers & Macdonald 2008). The conditional nature of chronic conditions patients' trust for clinicians, as well as the kinds of roles patients take given such conditional trust, are thus crucial to clinicians' experiences of chronic conditions healthcare.

Substantive space and thought is given to the role of the clinician in long-term conditions work within another seminal chronic illness text, *The Illness Narratives* (Kleinman, 1998). After thirteen chapters focusing on chronic illness patient experience, Kleinman alters "the interpretive emphasis" in the last three chapters, to focus on 'healers'. He suggests these chapters provide

> … a guide for caring for the chronically ill and as a program for altering the education of medical students and postgraduate trainees so as to improve such care. While there is much to admire and recommend in current medical practice, the care of chronic illness is not one of the great success stories of contemporary medicine (Kleinman 1998, p. iv).

He offers a number of vignettes of different types of clinician responses to the experience of practice in general, which he categorizes with titles such as 'the wounded healer', the radicalized revolutionary, the 'commoditized' healer, 'the cynic' and 'the sensitive neophyte' (Kleinman 1998, pp. 211-220).

Such roles are commonly suggested in analyses of medical roles, with Loewe et al suggesting that a physician managing diabetes may take the roles of "educator, the nagging wife, the compulsive doer and god", "adversary or authority figure" or driver of "a therapeutic alliance" (Loewe et al. 1998, p. 1272). Such categories emphasise the particularity of roles clinicians may adopt in long-term conditions work. Yet Kleinman is alone in stressing that "care of the chronically ill is difficult and burdensome for even the most attentive and gifted of healers" (p224). He particularly notes that there may be

> …frustration of trying multiple treatment plans without obtaining the desired results tires the practitioner as much as the patient. The very sense of compulsive

> responsibility essential to the care of acute illness and emergency exacerbation of chronic disorder may, over the long course, create chronic irritability and numbing exhaustion. Repeated treatment failure tests the physician's sense of competence until over time and with enough cases his sense of confidence is menaced (Kleinman 1998, p. 225).

In attempting to draw attention to how to do better chronic conditions healthcare, Kleinman may have inadvertently contributed towards negative perceptions of such work. The above study is medically-based, and includes limited discussion of positive experiences of working with long-term condition patients. It includes neither discussion of how other healthcare disciplines may perceive long-term conditions work, nor attempts to interview physicians passionate about good chronic conditions healthcare. My research follows Kleinman's cues, in paying attention to the experiences of clinicians, however broadens his focus from solely medical to all healthcare professionals working with people with long-term conditions; paying particular attention to those whose describe chronic conditions healthcare as a passion or particular interest. My research also prioritises clinician experiences, rather than taking an 'add-on' approach to more patient-focused research.

More recent literature examines the uptake of chronic conditions self-management support work by clinicians. Kirby et al explored "factors involved in patient activation for chronic disease self-management", and noted that "clinicians who had a defined role in chronic disease management and patient-centred and behaviour change skills" appeared more engaged with self-management support than those less familiar or enabled (Kirby, SE et al. 2012, p. 220). Whilst this study is focused on the broader range of chronic conditions healthcare, and not solely upon chronic conditions self-management; the access and referral barriers Kirby et al note in regional New South Wales are equally likely to occur in rural and regional Tasmania, and thus equally contribute to a sense, for some health professionals, that referral to chronic conditions self-management programs is "a lost cause" (Kirby, SE et al. 2012, p. 223).

The location of care, or what Langstrup refers to as 'chronic care infrastructures', also influences the healthcare experience. For chronic conditions in particular, "the home and the clinic are always intimately connected", and "the home with its actors, routines and spaces provides important allies in extending the chronic care infrastructures beyond the clinic" (Langstrup 2013). In drawing attention to the situated nature of healthcare practice, Langstrup notes that medication, knowledges and equipment need to be incorporated into any healthcare site including the home, and that these chronic care infrastructures need to be established and distributed

between multiple locations and actors. Similarly, Dew et al note that "understanding the home as a centre of medication practice decentralises the role of health advisors (whether mainstream or alternative) in wellness practices" (Dew et al. 2014). A shift in the location of care may therefore also result in shifts in professional identities.

3.4 Summary

In Chapter Three I examined the demographic, social and cultural milieu currently experienced by healthcare workers. Healthcare workers form a substantive portion of the Australian working population, and of the Tasmanian working population in particular. In rural areas, nurses are the most common form of healthcare worker; however, health and wellbeing data on Tasmanian healthcare workers is difficult to find. What data is available indicates that Tasmanian healthcare workers are likely to be sedentary, and (despite being healthcare workers) approximately half may be overweight or obese, with poor vegetable and fruit intakes.

As an ageing workforce, the increasing female participation rates within those healthcare professions which were not already female dominated have potential to further 'sandwich' potential workers, between familial (child and elder) care responsibilities and work commitments. Work-life balance has become an issue for management, although it is presently largely approached on a one-on-one basis. The people who form the potential chronic conditions healthcare workforce (ie the healthcare workforce as a whole) appear considerably more reflexive and discriminating than previous generation healthcare workforces, in selecting and maintaining particular work pathways.

Cultural changes, including changes in patient role, are contributing to changes in experience of healthcare work. There are longstanding understandings that care for people with chronic conditions is necessarily different (for example, "the care that is provided is largely long-term care, as contrasted with the acute, episodic care that characterizes treatment of isolated episodes of illness" (Somers 1987, cited Gillick 1995, p. 190); but there are no detailed studies of such work. Expectations of chronic conditions healthcare are changing at every level:

- at system level: where administrative and payment structures are being created to dictate particular kinds of chronic conditions responses (such as multidisciplinary teamwork and community-based care)
- at clientele level: where patients are increasingly more likely to be a 'member of a team', an 'expert patient', rather than solely a compliant subject; and

- at peer level: with systematic pressure to 'work as a team', healthcare professionals have expectations of each other (across disciplines and within disciplines).

Chronic conditions healthcare is therefore insufficiently theorised, and what descriptive analysis exists, is largely approached via disease-specific or tangential routes. The rise of chronicity within healthcare is clearly an issue, however the experience of it is not substantively discussed other than in patient experience literature. The experience of being a healthcare provider is generally given only little or peripheral attention. Rural healthcare literature provides more experiential accounts, however chronic conditions patient-focused literature also provides windows into what it may be like to do chronic conditions healthcare.

The literature discussed provides evidence that chronicity is increasing; however, that healthcare environments and broader social cultures appear to cause both patients and health professionals to deprioritise chronic conditions related action. In situations where other types of healthcare seem more pressing (such as emergency departments), or where healthcare is under pressure (for example, rural and remote healthcare), inactivity regarding chronic conditions may be both frequent and repeated, to the point where it may have long-term consequences for both individuals and healthcare systems. I have not been able to find literature, which examines whether this is actually the case, and if so, in what ways. In this thesis I do not seek to answer such questions, but rather to explore an even more fundamental question: what is the experience of doing chronic conditions healthcare for healthcare professionals presently at work in our healthcare system? It is this (more preliminary, more exploratory) research question ('what is it like?'), which may provide secure grounds and thematic indicators for future comparative investigations.

In a context where the clientele of healthcare systems are changing, from predominantly acute and short-lived illnesses to predominantly long-term conditions, an understanding of the experience of clinicians working within such contexts is important information for both policy and practice. In Chapter Four I outline the qualitative research methods necessary for the exploration of such a question.

4 Methodology and Research Methods

4.1 Introduction

In this chapter I discuss the conceptual framework, methodological influences and research methods used to investigate the experience of doing chronic conditions healthcare in rural areas. I describe the methodological influences and multiple methods used to pursue an interpretive inquiry: to explore health professionals' experiences of working with people with chronic conditions in rural and remote areas.

First I outline the research design, conceptual and methodological influences, and research parameters. I then explore the research methods: data collection and data analysis techniques. I then discuss the research ethics and ethical issues, before concluding with some reflections of participants on the research process.

4.2 Research design

The research was designed to address a research question about the experience of doing chronic conditions healthcare, as mentioned in Chapter One:

What is it like, and what does it mean, to be a health professional
doing chronic conditions healthcare?

As previously discussed, within the broader research question, research sub-questions which sought to elucidate strengths as well as issues within chronic conditions healthcare were determined:

RSQ 1: What are the issues for health professionals in doing chronic conditions work?

RSQ 2: What are the strengths of such healthcare professionals?

RSQ 3: What are the strengths of chronic conditions healthcare itself?

These questions were designed to elucidate the resources and attitudes which different practitioners (and professions) bring to chronic conditions healthcare: to tease out how healthcare professional roles are changing, given changing epidemiological profiles and cultural expectations of chronic conditions healthcare. The research aims to identify and express (1) pre-existing frameworks which influence chronic conditions healthcare (discussed in Chapter Five), and (2) practice styles which characterise healthcare professionals' ways of doing and experiencing chronic conditions healthcare (discussed in Chapter Six). Qualitative and

interpretive research approaches allow more sophisticated examination of such questions of meaning.

The research design draws on interpretive traditions within qualitative research (grounded theory, postmodern ethnography, and transformative research), as discussed below. The design is of an iterative process in keeping with inductive methodologies, where reflexivity in data collection, sampling, analysis and literature searching remain central. A circular process of collecting and creating data through multiple qualitative methods (**observation**, **semi-structured interviewing**, plus **film work** consisting of consultation videos and video-triggered interviews) created a rigorous reflexive process, involving:

- observation: of live clinical work and of consultation videos, interviews, and video-triggered interviews;
- analysis: of data through creation of and immersion in interview transcripts; and
- writing: through coding for and writing about themes, whilst simultaneously reviewing relevant literature.
- In keeping with grounded theory, the research functioned in a reflexive style (testing emergent themes as they arose), rather than complete immersion in a phenomenological hermeneutic circle process where feedback from all participants on emergent themes is specifically sought.

Different aspects of the research design enable different kinds of types of information. For example, observational data, of different styles used by healthcare professionals to work with similar patient issues, address the research sub-questions of issues and strengths. Interview data provided opportunities for clinicians to discuss their professional and personal histories, and how these contribute to their present approach to chronic conditions healthcare (addressing all three research sub-questions). Video-triggered interviews (as defined in Section 4.5.1 below) enabled elicitation of the subtleties of tactics within consultations, and within particular patient-professional relationships. Video-triggered interviews also provided an opportunity for clinicians to analyse their own clinical work. Relevant literature has been used as much in the form of data, as it has as background to the study, with "a progressive accessing and reading of relevant literature [as] a part of data collection" (Dick 2005) as well as analysis. This use of literature also satisfies grounded theory expectations for reflexivity (responsiveness to research participant needs including my own), and is a pragmatic solution to the changing literature inevitable within a long duration (part-time) candidature.

The logic of using multiple qualitative methods was two-fold: primarily to capture different aspects of the phenomena under investigation, taking a multi-dimensional approach to a multi-dimensional issue and crafting internal validity (see May, V 2010) re distinctions between multi-dimensionality, triangulation, and complementarity; also Kvale (1995) regarding social construction of validity). I also wished to extend my research skills beyond my then skillset, and adding a component of video-ethnographic work strengthened both the internal validity and my sense of the research as more than simply the reported perspectives of participants. Barry (Barry 2002) calls for the use of multiple methods as an aid to more truly rich description of the "multiple realities" of clinical work: "the aim is not to produce a tidy picture, but to allow for the messiness and tensions that exist in social reality" (May, V 2010, p. 3).

The research design thus incorporates the qualitative nature of the project, influential theories, processes of sampling and data collection, as well as writing and sense-making (analysis). By using multiple qualitative methods, and researching across multiple health disciplines, the research remained open to the contradictory aspects of contexts for chronic conditions healthcare which exist in everyday realities. However, the research also strives to maintain awareness of (and respect for) the unspoken need of participants for their stories to 'make sense'. In arguing that "social (and multi-dimensional) lives are lived, experienced and enacted simultaneously on macro and micro scales", Mason suggests that both micro and macro aspects of experience need to be explored. Just as "lived experience transcends or traverses dualisms" (Mason 2006), so the multiple research methods must be synthesized into a coherent whole. By incorporating observation, interviews and filmwork (consultation videos and video-triggered interviews), both the generation of interview data and the analysis of such data are deepened and problematized, transcending some of the limitations of single method projects.

4.3 Conceptual and methodological influences

Conceptually, this thesis can be described as interpretive, and draws on several interpretive traditions: grounded theory, ethnography and transformative research. I agree with Kincheloe (2001), who states that "[w]e occupy a scholarly world with faded disciplinary boundary lines" (2001: 683). Kincheloe continues,

> "… the frontiers of knowledge work rest in the liminal zones where disciplines collide. Thus, in the deep interdisciplinarity of the bricolage, researchers learn to engage in a form of boundary work" (Kincheloe 2001, p. 689).

Rural health, as a discipline, is necessarily interdisciplinary, engaging scholars from clinical, economic, sociological and educational backgrounds amongst others. This research is situated within rural health, and investigates the experiences of multidisciplinary rural healthcare

professionals. It thus inherently operates within a space of "learning from difference" (Kincheloe 2001: 687), questioning assumptions of particular healthcare and academic disciplines.

As a qualitative researcher within rural health, I am constantly confronted with differences, and utilise these as a kind of "defamiliarization process … to expand the researcher's interpretive horizons". In this I aimed to "not simply tolerate difference, but cultivate it as a spark to researcher creativity" (Kincheloe 2001: 687). As a researcher educated in multiple disciplinary contexts, I do however feel "less compelled to relate work to legacies of disciplinary theory" (Giacomini 2010, p. 127). Nevertheless, I do not wish to neglect theoretical richness. There are valid calls for more consideration of, and indeed more theory in rural health (Humphreys, Wakerman & Wells 2006; Humphreys et al. 2008; Bourke, Humphreys, et al. 2010). Theory matters to this research, in that I bring theoretical (ontological and epistemological) approaches to the research. I also concur with Giacomini that "qualitative research findings themselves are theoretical constructs: systems of ideas for understanding" (Giacomini 2010, p. 145). This thesis needs be made meaningful to readers who may not share a common theory base (qualitative or epidemiological), and who are therefore "forced to compare not only methods but also differing epistemologies and social theoretical assumptions" (Kincheloe 2001: 686). It should therefore be understood as a rural health thesis within an interdisciplinary and applied research context, incorporating theoretical approaches from multiple disciplines.

This research sits within interpretive, naturalistic inquiry traditions; and qualitative research frameworks guide both the research and the findings. In this, I aspire to "a more modest approach, which recognises the limited nature of theory but still values its usefulness" (Ezzy 2002, p. 2). All research involves inductive and deductive cycles; however, the emphases on these vary according to the stage and style of research. This research maintains particular maims of inductive research as theoretical underpinnings of the research design, namely that:

> "1) There are multiple constructed realities that can be studied only holistically. Thus, reality is complex, contextual, constructed, and ultimately subjective.
>
> 2) The inquirer and the 'object' of inquiry interact to influence one another; indeed, the knower and known are inseparable.
>
> 3) No *a priori* theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data" (Lincoln and Guba 1985, cited Thorne, Reimer Kirkham & O'Flynn-Magee 2004, p. 5) p5).

As a study of experience, the research thus incorporates aspects of various interpretive research paradigms, but is principally guided by the tenets of grounded theory, ethnography and

transformative research. Each brought specific assets to the research, and will be dealt with in more detail below.

4.3.1 Grounded Theory

Whilst not purely grounded theory, this research is strongly influenced by its tenets. According to Lingard et al, "key features of grounded theory are its iterative study design, theoretical (purposive) sampling, and system of analysis" (Lingard, Albert & Levinson 2008, p. 459). This research adheres to these, in particular emphasizing iterative (reflexive) analysis. Grounded theory also considers it crucial to study real activity (Charmaz 2005 [1983]), and to generate theories 'grounded' by systematic analysis of empirical data (rather than developing and/or testing hypotheses independent of empirical experience). Grounded theory thus gives this research a rationale for focusing on the present actions of healthcare professionals and maintaining a continuously evolving research design; whilst attempting to capture "broader social systems of ideas" and present "an abstract, stylized version of the commonplace theories that prevail in the social world studied" (Giacomini 2010, p. 139).

The data collection phase of this research is particularly influenced by grounded theory, in that it involves "cycles of simultaneous data collection and analysis, where analysis informs the net cycle of data collection" (Lingard, Albert & Levinson 2008, p. 459). For example, the semi-structured interview guide developed through six versions during the fieldwork, as participants suggested further areas which needed to be explored. In addition, as in more recent grounded theoretical work, this research used an initial literature review to create sensitising lenses prior to fieldwork. However, as a study of the meaning and lived experience of doing healthcare work, this research is also to some extent phenomenological in character. Phenomenology gives this research its emphasis on the importance of understanding of being, in particular through individual inner sense-making (Giacomini 2010, p. 138). Phenomenological approaches focus on a person's experiences, "methodologically capturing and describing how people experience a phenomenon – how they perceive it, feel about it, and make sense of it" (Sadler et al. 2006, p. 79), and "enlarging the experiences and attempting to understand it [sic] in the complexity of its context" (Karlsson, Arman & Wikblad 2008, p. 564). However phenomenological approaches prioritize the researcher's subjective, phenomenological knowledge; alongside 'co-created' understandings where "participants and researchers jointly create phenomenological accounts" (Giacomini 2010, p. 138). This research stays poised between the more interpretive end of phenomenology and the less descriptive end of grounded theory.

I note concerns with grounded theory and its use as an 'excuse', or "rhetorical sleight of hand by authors who are unfamiliar with qualitative research and who wish to avoid close description or illumination of their methods" (Suddaby 2006, p. 633). For me, the concern is more that grounded theory approaches assume that an abstracted, theoretical understanding is possible; a perspective which from a phenomenological viewpoint is less tenable. As a researcher, I am aware I have "tapped only one version of a story[,] and that there might well be many as yet unarticulated layers of meaning underlying the version presented." (Thorne 2009, p. 1183). In this research, combining phenomenology with grounded theory has softened the harder edges of both, enabling an inductive interpretation of the cultural and individual contexts which shape chronic conditions healthcare.

4.3.2 Ethnography

An ethnographical approach is important to this research, in that it enables me to go beyond the somewhat individualistic focus of much grounded theory. In taking an ethnographic attitude, my research focuses on the broader social and cultural contexts that shape chronic conditions healthcare. It therefore fits within Savage's definition of an ethnography:

> … any small scale research that is carried out in everyday settings; uses several methods; evolves in design through the study; and focuses on the meaning of individuals' actions and explanations rather than their quantification (Savage 2000, cited O'Reilly 2005, p. 2).

Ethnography encourages immersion in the field, and normally utilises multiple methods: typically participant and non-participant observation, formal and informal interviews, and the gathering and analysis of texts, tools or other objects associated with people (Picken 2010). Willis and Trondman (2000) specify that an ethnography should "involve direct and sustained social contact with agents, and richly writing up the encounter, respecting the irreducibility of human experience"; "presenting and explaining the culture in which this experience is located, but also acknowledging that experience is entrained in the flow of history" (Willis & Trondman [2000], cited O'Reilly 2005, p. 2). Grounded theory research too often utilises multiple methods, however ethnography provides this research with grounds for retaining its focus on cultural aspects "which may subtly change the questioning and therefore, potentially, the analysis" (Wimpenny & Gass 2000). A particular advantage of ethnography is that people's work is studied in situ, rather than relying solely on participant reports (for example, via interview data). This research involves direct (non-participant) observation, and in some cases, recording activities via field notes or video-recording, which were used in later discussions or interviews with the health professional.

While there is a long history of medical and nursing ethnographies focused on culturally different health and illness experiences (see Kleinman's overview of twentieth century medical ethnographies 1997, p193-256; Roper & Shapira 2000, pp. 2-27 re nursing ethnographies), observation of allied health professionals is less common. Observation of health professionals is most commonly undertaken by people within or aspiring to the same profession, for example for training contexts (within undergraduate placements) or for certification (assessment of interns). I wanted to bring a fresh eye to the observation of a broad range of health professionals, and enrich my interview data by committing to undertaking observation as well as interviews: "descriptive work includ[ing] conversations, documentary evidence, and observations of practices, behaviours, rules and beliefs"(Picken 2010). Having 'in situ data' as well as interview transcripts without doubt fruitfully affected the analysis.

4.3.3 Transformative research

Additionally, the research incorporates some principles, if not practices, of transformative research. While the exploratory nature of the topic was not suited to action research, I wanted to maintain the primacy of connection with research participants and foregrounding of their points of view, that transformative research mandates. This research was designed and constructed, not as participatory action research, but with a transformative expectation. Researching chronic conditions healthcare inherently involves bringing chronic conditions healthcare to people's attention. The focus was initially on the experience and meaning of chronic conditions healthcare, not on defining chronic conditions healthcare. However defining chronic conditions healthcare became a big part of the research, and discussing this with research participants a transformative undertaking.

I agree with Heron and Reason, when they argue for a 'participatory worldview', which "affirms the primary value of practical knowing in the service of human flourishing" (1997). They argue that a purely constructivist position fails to account for experiential knowing. Similarly,

> … the interpretive tradition seeks to understand phenomena from the viewpoint of the people themselves. People's active response to social reality possesses meaning, and research involves engaging with people to discover the meaning behind the action in particular situations. [In] participatory research, … participatory researchers seek not only to discover meaning but to explore its properties with the people studied. Data are generated and verified with the people themselves. The research subjects become research participants, working in partnership with researchers to engage in a process of defining and interpreting data." (Fleming & D. 2004, p. 164).

While this study has not formally incorporated the capacity for research participants to 'define and interpret' the data, I engaged in continual dialogue with rural health professionals during the fieldwork and early analysis. Through presentation of this and related material at rural health conferences and primary healthcare researcher symposia (Spinaze 2009c, 2009b; Spinaze & Griffiths 2012), and sociology, nursing and geography postgraduate student discussion groups (2006-2014), I continuously sought feedback for incorporation into the developing thesis. I have also consulted departmental and professional key informants periodically throughout the research and writing processes.

I designed this research with the intent that representatives and key informants, if not actual participants, should be able to determine as much as possible the content, context and use of the research. I wanted the process to provide an emancipatory voice for a type and style of work currently underemphasised. In developing the research topic, I consulted broadly with rural health professionals and Department of Health and Human Services staff. I aimed for the research to be

> (1) ethical--with attention to human rights and social justice;
>
> (2) emancipatory--contributing to reduction of oppression;
>
> (3) empowering--serving marginalized and disadvantaged groups; and
>
> (4) holistic--identifying relationships between parts and the whole, micro and macro contexts, local and global issues. (Deshler & Selener 1991)

In particular I was concerned that this study "blend scientific inquiry with social action by creating knowledge that is relevant to the research partners' needs and interests" (Lingard, Albert & Levinson 2008, p. 461). I consider the research participants to be my research partners – my guides, mentors, and touchstones; as I attempt to understand and convey their world. However, by asking to observe them, and asking questions about chronic conditions healthcare, I have inevitably drawn their attention to that particular part of their own work. In this sense, this research remains transformative.

4.4 Research methods: data collection and analysis

In this section of the thesis I delineate the research methods utilised for data collection and data analysis, despite noting that "data collection in qualitative research is not something easily separated off from data analysis" (Ezzy 2002, p. 73). The data collection section describes the sampling logic, recruitment processes, and justifications for observations, interviews, consultation videos and video-triggered interviews as the primary data collection methods. A final data set and table of basic participant demographics are also outlined. The data analysis section examines thematic analysis as a method, and outlines this research's approach.

4.4.1 Data collection methods

Review of literature

Literature searches were the first part of data collection, with literature was sought before, during and after fieldwork (throughout candidature). As with fieldwork sampling (see below), purposive searching rather than comprehensive or systematic literature search structures determined the types of reading material sought and selected for incorporation. The databases Proquest, Scopus, Informit (APA-FT, Humanities & Social Sciences Collection, APAIS-Health, Health & Society), PubMed and Web of Science were searched; to allow inclusion of relevant articles from health care, sociology, specific health professions (medicine, nursing and allied health) and rural and remote health. Terms like 'chronic condition', 'chronic disease', 'long-term disease', 'long-term condition', 'long term', 'experience', 'professional', 'clinician', 'provider' and so on were used in various combinations. 'Chronic illness' was not used regularly, as it tended to generate largely patient-focused material (perhaps due to the sociological distinction between 'disease' as biomedical and 'illness' as experiential). However, occasional searches using 'chronic illness' were also conducted.

Content alerts throughout the duration of the research helped in maintaining currency and continued to generate relevant material until late in the writing process. One particular journal - *Chronic Illness* - was particularly influential, and I monitored it regularly. I considered it important to keep patient perspectives and illness narratives in mind, at the same time as I focused on exploring the experiences of clinicians interfacing with such narratives. Patient chronic condition trajectories also suggested possibilities for parallel clinician long-term conditions work trajectories (as discussed in Section 2.4.1).

Sampling

In keeping with grounded theory traditions, purposive theoretical sampling rather than statistical grounds determined the final sample. In pursuing an iterative study design, "the sampling process proceeds on theoretical grounds: the sample is not set at the outset but is selected purposefully as the analysis progresses; participants are chosen for their ability to confirm or challenge an emerging theory" (Lingard et al 2008: 459). I agree with Thorne et al and Morse, who contend:

> … people who have lived with certain experiences are often the best source of expert knowledge about those experiences (Morse, 1989b). However, …not all people who have such experiences will make good research participants (Morse, 1989a). […] Thus, we believe that an interpretive description that is meant to generate nursing practice knowledge will require purposeful selection of research participants whose accounts reveal elements that are to some degree shared by others."(Thorne, Kirkham & MacDonald-Emes 1997, p. 174)

The sample selection thus proceeded with two aims: firstly to achieve diversity, and secondly, to discern common elements.

In aiming for diversity, I addressed the requirements of the research questions to explore a range of views and experiences. I believed it most effective for the research to access a good representation of the range of health professions likely to be found or accessed by people with chronic conditions living in rural and regional Tasmania: that is, 'typical' healthcare workers in 'typical' contexts. I did include one participant who takes an unusual approach to one aspect of his private practice (a GP who provides healthcare to people solely in their own homes, and does not have a practice office or 'rooms'). This participant functions as a contextual outlier, in that I am not aware of any other GP who presently does only home visits. However, the content and range of his practice, as viewed during observation, did not appear atypical.

I went to some lengths to include specific professions (maintaining contact with early respondents over some months until they were available, and in two cases across a couple of years), and to maintain participation across all three Tasmanian regions. Data collection ceased when 'theoretical richness' (Rice & Ezzy 1999) rather than 'saturation' determined an appropriate number of participants. The demographics of participants demonstrate considerable breadth, yet are typical of rural health professionals (largely female, with an ageing profile – see Appendix 3 'Complete List of Participants'). The material generated indicates thematic sufficiency.

In a purposive sampling context, theoretical saturation is often considered to have occurred when,

> (1) no new or relevant data seem to emerge regarding a category;
>
> (2) the category development is dense, insofar as all of the paradigm elements are accounted for, along with variation and purpose;
>
> (3) the relationships between categories are well established and validated. (Strauss and Corbin 1990: 188).

However, with theoretical richness as the criteria for cessation of data collection, thematic sufficiency was achieved well prior to completion of interviews. As experienced by others,

> … [i]n the case of the current research, there were still a number of categories and experiences that could have been fruitfully explored and that were not 'saturated'. However, the central categories of the analysis were theoretically saturated. Limited time and resources prevented a more extensive exploration. (Ezzy 1996, p. 78).

The last few interviews were undertaken to explore and consolidate themes emerging from analysis of earlier interviews (as typical for later-stage grounded theory research), and to broaden the range of professional profiles within the research. Theoretical richness was such that there

was no requirement for further thematic or theoretical material; however, where valuable insights were generated, these were incorporated.

In maintaining a focus on rural health professionals, I created inclusion criteria. One such was the requirement to be a healthcare professional (someone paid wages to work in healthcare). This meant that, when one healthcare professional was accompanied by a volunteer throughout the observed shift, and strongly recommended that I interview the volunteer as well as himself, I did not consider it necessary to the project. The role of volunteers in the Tasmanian healthcare system is not to be denied or minimised, in particular in the context of rural paramedic work (which in some cases cannot be undertaken without the presence of volunteers): however volunteers are not the focus of this project. Aspects of chronic conditions healthcare which involved volunteer work by staff as 'formal' or 'informal' carers are not discussed in this thesis, other than in their personal roles as carers (see Section 7.4).

A potential exclusion criterion which arose was the question of who is 'rural'. In keeping with participatory research principles, this research relies on participant definitions of rurality, noting that on some criteria the whole of Tasmania is considered rural (see Section 1.5.2). Invitations were sent state-wide to primary health care workers (through DHHS), and to general practitioners (through GP Tasmania). Participants thus identified themselves as either "a rural or remote health professional" or "a health worker in rural, remote or regional Tasmania" (both phrases used in Health Professional Invitation to Participate, see Appendix 1A).

One research participant was resident in Hobart, another was a part-time resident in an outer northern suburb of Hobart, and two were in Launceston (all regional centres by ASGC classification). However all twenty-six participants worked either wholly or regularly in rural and/or remote areas at the time of interview or observation. The least amount of rural work was done by one allied health professional, who had been servicing rural communities for eighteen years on a part-time basis (one day a week) while living in an urban location. Because of the duration of her commitment to rural practice, and given the Tasmanian prevalence of hub and spoke models of allied health service for small population areas, she was included in the research. Given hub and spoke models of service, and the relatively small geographic area within Tasmania, it is unsurprising that some health professionals reside in urban locations, yet consider themselves rural practitioners. For the purposes of this research, I focused on the rural and remote aspects of practice during observation and interview for any clinicians who were currently

working in both rural and urban locations. Location of residency was also discussed only in terms of its impact on rural/remote practice.

Recruitment

Recruiting of the sample was initially through informal networks: personal contacts and research facilitators (people who were not research participants in the formal fieldwork sense, but who nevertheless spoke with me about their experience of chronic conditions healthcare. In some cases these early participants allowed me to observe them working where no patients were to be present, for example, at staff training and information sessions); which helped determine the need for observation as well as interview with the research methods. Research facilitators functioned as expert advisors during the thesis topic development, key informants, and (in two cases) pilot participants for fieldwork techniques (for the first observations, consultation video, video-triggered interview and semi-structured interview; with one practice nurse and a GP).

Fieldwork episodes that were initially undertaken as pilot studies were later incorporated into the final sample, as no substantive difference in the data content was discernible. Beyond informal networks for the pilot stage, letters of invitation promoting the research and asking for volunteers to participate were emailed by
(1) Department of Health and Human Services (DHHS, Government of Tasmania) to all primary health workers in the then North, South and North-West regions;
(2) the then Tasmanian Division of General Practice (later General Practice Tasmania, now Tasmania Medicare Local) to GPs throughout Tasmania.

Letters of invitation (for both clinicians, and for patients whom clinicians approached to be involved in the filmwork) had a basic definition of terms such as 'chronic conditions' (see Appendix 1A), but did not exclude clinician contributions to such definitions or re-definition. At a later date (subsequent to separate legal and internal departmental approval processes), a similar letter of invitation was emailed to paramedics through Ambulance Tas within the DHHS, and a short news item promoting the research and inviting participation accepted for the Pharmacy Guild Tasmanian branch and Pharmaceutical Society of Australia e-newsletters. I also attended a rural general practice update weekend to promote the research. The recruitment process therefore largely involved accessing volunteers through intermediary organisational bodies (rather than key informants), however earlier participants were also requested to suggest a colleague who might be interested (that is, 'snowball recruitment').

Recruitment for the filmwork component (consultation videos and video-triggered interviewing) was both more difficult and more time-consuming. Not only did filmwork require the interest and consent of the health professional concerned, but also a process where health professional participants were asked to suggest and invite suitable potential patient participants (who then went through a separate information and consent process prior to any contact with myself). I believe recruiting for the filmwork component was more difficult partly because:
(1) There is not a strong culture of use of video within the community healthcare sector in Australia. This is in contrast to the UK, where up until fairly recently GPs were expected to submit 20 consultation videos as part of fellowship certification (Tate 1997).
(2) The video component of the research was not nested within a broader video ethnography, which enables greater participant familiarity with both the processes and the products of video-based research (Carroll, Iedema & Kerridge 2008).
In the end, as an additional method rather than one which was to generate the main body of the research, recruiting for the video-triggered interviewing component was restrained in favour of a focus on recruitment for the more central observation and interview methods. Three consultation videos were made, and three video-triggered interviews conducted, with one participant contributing twice. Towards the end of the recruitment period, particular disciplines were targeted for recruitment to ensure representation across the spectrum of health professions normally present in rural areas.

Observation

Observations were made prior to semi-structured interviewing wherever possible, initially to gain trust and assure relevance of the early interview guide; later to build rapport, broaden understanding of chronic conditions healthcare in different professional contexts, and to problematize initial analyses. Kelleher describes advantages of observational methods as the 'forcing' of familiarity with the subject, allowing "previously unnoticed or ignored aspects to be seen", and that "people's actions are probably more telling than their verbal accounts" (Kellehear 1993, p. see also Atkinson & Coffey 2002).

Observational data were obtained through sitting in on individual and group consultations; in rural hospital, outpatient, private business and community health settings. Settings included offices, consultation rooms, clinical treatment rooms, patient homes, rural hospital wards, offices and central nursing workstations, team meetings (including education and planning sessions, handovers and corridor conversations), staff common rooms, and work automobiles driving between appointments. The process involved "systematically watching and recording people's

behaviours, clothing, expressions and interaction in a particular location" (Rice & Ezzy 1999, p. 104), after seeking permission to be present in clinical settings.

Field notes were recorded in small pocket-sized notebooks, and (while inherently an incomplete record of a day's activities) noted instances of chronic conditions healthcare, particular phrases used and activities undertaken during consultations by patients and health professionals, and researcher reflections. The concept was to at least partially have a sense of immersion in the field (akin to ethnographic methods), and to observe "what people do *as much as what they say*" (Picken 2010, p. 2, emphasis added).

Interviews

Interviewing was the substantive focus, and generated the largest amount of data, within this research. The impetuses for the interviewing style were grounded theory and ethnographic; specifically in that:
(a) the semi-structured interviews attempted to gain insight into the lived experience of doing chronic conditions healthcare as a rural healthcare professional,
(b) in keeping with grounded theory, the interview guide changed, undergoing six iterations during the four years of fieldwork, and
(c) the duration and frequency of contact for the majority of interviews was substantially more (thus more ethnographic) than other types of interview project.

Given that I had spent time in most of the research participants' clinical spaces, I felt to some extent inspired by Carpiano's 'go-along' interview method (Carpiano 2009; Garcia et al. 2012), where the interviewer records participant conversation during a walk through significant areas. However the interviews were all recorded as 'sit-downs', in a quiet space chosen by the research participant (often the clinician's room). The interview content is thus (as appropriate to the research topic) more focused on "people's biographies and perceptions of self and others" (Carpiano 2009, p. 266) than it would have been if the interviews had taken place as tours of clinical spaces.

Some interviews took place at work (in the participant's own clinical space or an adjacent quiet office), some at work in open-plan office spaces, some at coffee shops or restaurants, some at private homes, one in a mall, and one at the participant's non-health (additional work) location. Two interviews were done by phone: one by preference, and one when clinical duties within fieldwork observation interrupted an attempted interview, and it was decided that it was easier to complete it after hours by phone. One interviewee was accompanied by his spouse during the

interview, and another interview was undertaken with three participants present. Interviews took between half an hour and 2.5 hours, with most about 75 minutes in length.

As with Kvale's *InterViews* (1996), the interviews were expected to be "first and foremost interaction, a conversation between the researcher and the interviewee" (Sherman Heyl 2001, p. 373). Holstein and Gubrium also suggest that the researcher and interviewee are "active creators in all phases of the interview process" (Sherman Heyl 2001, p. 373) p373, where the interviewer may ask questions but so might the research participant (see also Fontana 2002, Holstein 1995, p. 29). The semi-structured interview guide (questions and prompts) functioned "more like framing devices that the respondent might follow" than direct "catalysts for the reflex-like production of answers" (Holstein 1995, p. 29). The research participant was invited to "speak to the interactional and informational challenges of the immediate circumstances" (Holstein 1995, p. 28).

At times interviews verged into autobiographical exchange, reminiscent of feminist geography strategies, where "[o]ffering stories of your own experiences as a way of eliciting the same from others" (McKay 2002, p. 193) may be a formal part of research, as well as of establishing rapport. However, given that auto-ethnography had been excluded from the research methodology, I was careful my own stories did not 'condition' the research participant into shaping their material too much towards a perceived expected narrative. I did not use my own nor other research participants' stories early in an observation period or in an interview, but reserved them for the 'winding up', 'theme testing' or 'consolidation' stages of interviewing, which sometimes occurred after the formal interview (after the recorder had been stopped). I was often invited directly (in particular asked by one participant) "what did the others say?". Fortunately this was early in the research (the second participant immediately after her interview), so I was able to answer honestly that it was early days, and I didn't yet know. Later, when asked this question, it was appropriate to relay others' (anonymised) experiences and take the opportunity to 'member-check', thus revisiting the grounded theory approach of the research where "the ongoing analysis … influence[s] the questions that are asked"(Wimpenny & Gass 2000). It was also an informal validating of experience, in the way that group work within action research more formally commits to. Participants appear to want to know that their stories were shared experiences: that they were not alone.

It is important to note the research design did limit sole reliance on interviews as the only form of data collection. Husso says interviews

> … do not give us direct access to facts. As Silverman (2006) notes, interview data should be understood as an opportunity to explore the contours of a particular discourse rather than provide an unblemished view of reality (Husso & Hirvonen 2011, p. 6).

The research design thus incorporated observation and consultation videos as integral to the final conceptions, derived from ethnographic and transformative research leanings.

Video-triggered interviews

Pink argues while ethnographers should not be obliged to make the visual central to their work, a consideration of the visual is highly important in any ethnographical research:

> "[I]mages are as inevitable as sound, smells, textures or tastes, words or any other aspects of culture and society" (Pink 2007, p. 21).

Having considered more purist ethnographic options, I concluded the research questions were best served by a primary research process of semi-structured interviewing, in addition to workplace observation. However, inspired by Raingruber (Raingruber 2003) and Carroll (Carroll, Iedema & Kerridge 2008), I extended the research to include a small pilot process incorporating video-triggered interviews. Comparable to the increasingly popular technique of photo elicitation, video-triggered interviews are a form of video elicitation. Creating a video-triggered interview involves videoing people's work, and then using the footage to generate reflections on practice, documented as an audio-recorded interview. These audio recordings are then transcribed to provide textual data, used in this research to further understand the complexities of relating to and working with a person with one or more chronic conditions.

By using a process similar to what Raingruber calls 'video-cued narrative reflection', this research takes a new angle on health professional work. First, I have chosen to document something rarely seen (private consultations), and second I have enlisted the filmed health professional in interpreting the footage. In Raingruber's words, video-cued reflection is a useful approach for accessing relational, practice-based and lived understandings as,

> …watching videotaped interactions, participants are able to re-collect, re-experience, and interpret their life world. Video-cued narrative reflection allows participants to be simultaneously engaged and reflective while describing significant understandings. By inserting audiotaped reflective commentary of participants into the original videotape transcript, contextual meanings can be located and articulated more easily. Although not appropriate for all types of research, this approach offers promise for certain studies." (Raingruber 2003, p. 1155) p1155

Iedema et al (Iedema et al. 2006) discuss the role of video-based research methods, in particular in contexts with shifting bureaucratic requirements. Their title, 'Visibilizing Clinical Work: Video Ethnography in the Contemporary Hospital' (Iedema et al. 2006), emphasises the point that clinical work is generally invisible, undertaken in private settings with only a 'patient' and a 'health

professional' present. I have emulated the method Iedema et al used: "[v]isual data gathered as part of that project … to specify issues which have thus far arisen" (Iedema et al. 2006, p. 156). In choosing to do a video-based component, I support their argument that "video-based research may provide staff with new resources and opportunities for shaping their increasingly public and visible work practices" (Iedema et al. 2006, p. 156): that making clinical work more visible creates opportunities for improvement. While their research project was hospital-based, both their research and mine "[focus] on negotiating understandings about existing care practices" (Iedema et al. 2006, p. 156). Video-triggered interviewing was thus a useful method to employ, in attempting to visibilize a less prominent style of practice.

Three consultations between health professionals and pre-selected chronic conditions patients were filmed, and video-triggered interviews conducted subsequent to the filming, using the consultation footage as triggers for in-depth interviews (see Appendix 5 for an example of a transcribed video-triggered interview). Analysis was primarily of the interview transcriptions (that is, thematic analysis, as with the semi-structured interview transcripts). However having the consultation videos also enabled a level of visual analysis, with participants commenting on their own interaction styles and posture. While neither the video component nor this research as a whole were focused on chronic conditions healthcare skills, using video-triggered interviews created an opportunity for health professionals to explore at a deeper level and explain (to themselves as much as to me), how it is that they do chronic conditions healthcare, and under what conditions. In the same way that doing observations deepened the potential for the interview data, using consultation videos created the opportunity for practitioners to observe and discuss their own practice; thus strengthening the transformative aspects of the research. Consultation videos also gave me the opportunity to extend or repeat my observation of particular clinicians' work, and thus create more detailed analysis for those cases.

Participants: final data set

The final data set comprised material from twenty-six health professional participants: 25 semi-structured interviews (audio recordings and transcripts), 19 occasions of observation (field notes, memos, and audio recordings of researcher responses), three digital videos of chronic conditions consultations, three video-triggered interviews (audio recordings and transcripts), and some clinical ephemera (such as clinic brochures, consultation note templates, chronic conditions management plan templates). Twenty-two of twenty-six participants were female, and sixteen were mid-career (aged 30 to 55). Interestingly, more than a third (twelve) either had chronic conditions themselves, had carer responsibilities for someone with a chronic condition, or a close family member (first degree relative, some residing with them) with one or more chronic

conditions. Some impacts of this personal experience of chronic conditions are discussed in Section 7.4.

The full list of participants, and the research methods in which they were involved, are presented in Appendix 3.

4.4.2 Data analysis method

In analysis of its data, this research diverges from its grounded theoretical roots, in that it utilises thematic analysis rather than grounded theory analysis. Thematic analysis is appropriate to an exploratory study into an area, which has not been clearly defined; and is most clearly defined as analysis which "aims to identify themes within the data" (Ezzy 2002, p. 88). Like grounded theoretical analysis, thematic analysis is inductive and emergent, and although "general issues […] of interest [may be] determined prior to the analysis", no prior determination is made of "the specific nature of the categories and themes to be explored" (Ezzy 2002, p. 88). This research nevertheless aligns with Dick, who states that

> What most differentiates grounded theory from much other research is that it is explicitly emergent. It does not test a hypothesis. It sets out to find what theory accounts for the research situation as it is. In this respect it is like action research: the aim is to understand the research situation (Dick 2005).

Thematic analysis in this research incorporated examining the data from the beginning of collection, fieldwork immersion, memo-making as a reflective process (both immediately after interviews and during later analytical phases), first pass analysis (noting of topics of interview content within interview transcripts), grouping of interview quotes into those topic areas and categorizing of those topics into broader themes, and refinement of those themes into the sections presented in Part Two. In some cases, interview questions became thematic categories in their own right, however most themes derived from syntheses of multiple interview material. The following discusses the thematic analysis techniques employed in more detail.

Immersion with the research data and research site is one process traditionally used to create rigorous qualitative research (see Holloway & Wheeler 2010, p. 5). Rice and Ezzy state that qualitative data analysis "should begin at the beginning of the study… [that is, it is] part of the research design, part of the literature review, part of the theory formation, part of the data collection, part of the data ordering, filing and reading, and part of the writing" (Rice & Ezzy 1999, p. 191). My research thus commenced analysis as part of the initial "strategy of 'calculated chaos'" (Lofland and Lofland 1971, cited Rice & Ezzy 1999, p. 191), with data collection, data

readings and re-readings a crucial part of the analysis process. Thorne et al concur, suggesting that "breadth is more useful than precision in the earliest coding and organizing processes" (Thorne, Reimer Kirkham & O'Flynn-Magee 2004, p. 14).

In creating the research design I incorporated opportunities for immersion beyond the normal 'participant observation and interview' structure: by extensive observation, by more than one interview where an interviewee requested it, and by creating consultation video recordings and video-triggered interviews (as well as transcripts of both these). The filmwork created particular depth with participants who had already participated in normal observation and semi-structured interview. Once the initial fieldwork had commenced, I made memos to myself after each observation or interview, generally summarising my response to the day, the person, and the observation or interview. As I got further into the fieldwork, these memos also functioned as 'contact summary sheets', guiding planning for the next contact; but also suggesting themes, and forming a basis for data analysis (Miles & Huberman, cited Silverman 2010, p. 232).

An ethical requirement is to have the transcripts as accurate as possible (see Poland 2002) and for me, this meant increased immersion in the interview recordings. I created and/or reviewed every transcription in detail, re-familiarising myself with an interview by listening to the recording at the same time as checking the transcript, re-punctuating for transcript stylistic consistency (especially where transcribing had been outsourced), and doing first pass analysis: immersion in the text and 'memo making' (see also Charmaz 2002, p. 687).

Qualitative researchers describe the above process of making notes as 'coding'; "reading through a manuscript for 'first impressions' " (Rice & Ezzy 1999, p. 199). While the simplicity of a single verb is tempting, I do not believe that it accurately describes my early analysis, which more takes the form of active reading ('reading with a pencil in hand'). In this I follow Morse and Thorne et al, where they recommend, "analytic techniques … that encourage repeated immersion in the data prior to beginning coding, classifying, or creating linkages. These analytic procedures capitalize on such processes as synthesizing, theorizing, and re-contextualizing rather than simply sorting and coding" (Morse 1994, cited Thorne et al 1997: 175). After the initial stage described above, I "moved between coding lines, paragraphs, interactional events, narratives about episodes, and the structure of the interview as a whole" (Ezzy 2002, p. 91), "experiment[ing] with a variety of conceptual labels, or categories" (Ezzy 2002, p. 89). In this way the analysis also moved into grounded theoretical techniques such as 'constant comparison', where "[a]s issues of interest are noted in the data, they are compared with other examples for similarities and

differences" (Lingard, Albert & Levinson 2008). An example of early analysis of one of the video-triggered interviews is provided (see Appendix 5).

In an 'iterative exchange', "emerging theoretical constructs" were "continually … refined through comparisons with 'fresh' examples from on-going data collection, which produces the richness that is typical of grounded theory analysis" (Lingard, Albert & Levinson 2008, pp. 459-460). By concurrently analysing fieldwork data at the same time as doing further fieldwork, I took advantage of simultaneous data collection and analysis; allowing insights gained en route to influence further data collection. Equally, undertaking comparisons between fieldwork occasions allowed me to discern "eccentricities from commonalities" (Thorne, Kirkham & MacDonald-Emes 1997, p. 174), prioritising utilising data with shared elements, whilst not excluding 'outlier' examples as potential representatives of the breadth of response.

The visual aspect of the research, the filmwork, aimed to generate supplementary in-depth textual data, rather than solely create data for visual analysis. The video recordings were thus used to stimulate interviewee reflection, as well as provide material for initial analysis. Visual analysis was also undertaken, for example via making notes during observation periods or whilst watching consultation films (visually catalysed 'memos'). Dyer suggests a useful checklist of categories of bodies (age, gender, race, hair, body), manner (expression, eye contact, pose – standing or prone and so on), activity (touch, movement, positional arrangements and communication), props and settings; which provided an entrée to interpretation of visual images (Dyer 1982, cited Rose, G 2007, pp. 80-82). This list was used to do preliminary visual data analysis.

Such momentary observations of visual information were the first steps in visual data analysis: jotted down observations (more 'neutral' descriptions of consultation events or contents) alongside perceptions (interpretations, queries about practice etc). These visual analyses were often used to generate questions, triggers or prompts within interviews; which were usually soon after the observation or filming period. The perceptions in particular (tentative understandings or interpretations) of moments during consultation films formed a partial basis for interview interactions – "when you did x with patient y, did you intend…?". While observing consultations engendered more immediate engagement during interviews with research participants, showing participants videos of their consultations prompted talk about different things. The consultation videos (as with photo elicitation research methods (Oliffe & Bottorff 2007) provided a focus for both micro and macro aspects of the issues of working with people with chronic conditions, in a way that interviews alone did not. Interviews where I had not observed the participant working

also came to feel less thorough than either video-triggered interviews, or observation-based interviews. Through video elicitation, video-triggered interviews created a different depth, although a similar style, of data to the rest of the interviews. The consultation videos also provided me with an opportunity to analyse components of information at more leisure, than when I was reliant on 'live' observation.

The analysis process also involved stepping back from minutiae to return to looking for the big picture: over-arching thematic directions. This final stage of analysis (concurrent with writing the thesis) also heeded Thorne et al's caution, that "[s]taying overlong in the microscopic view of the trees has a tendency to blur one's perspective on the forest" (Thorne, Reimer Kirkham & O'Flynn-Magee 2004, p. 14). While it may be compared to formal axial coding 'dimensions', retaining the focus on 'big picture stories' (as presented by participants rather than pre-determined dimensions) helped the analysis avoid the danger of focusing on "issues related to his or her [researcher] interests rather than the issues that concern the participants" (Ezzy 2002, p. 91). Results are presented as findings, however the hypothesis 'that chronic conditions healthcare is an unvoiced but major subset of primary healthcare work' emerged inductively during the early phases of the fieldwork. This became a hypothesis which, to some extent, was tested and confirmed during the rest of the fieldwork and analysis. In order to maintain focus on clinician voices as well as my own analysis, informal member checking took place with a representative sample of health professionals (some new, and some original participants) throughout the research.

Those original participants who expressed interest and were contactable were sent a draft copy of the thesis, and their feedback was incorporated into this thesis and into future publications where possible. The difficulty within the PhD writing context is to present both a reasoned analysis (a sum of the individual wholes) in light of a focused theoretical and contextual awareness of chronic conditions healthcare, whilst retaining both a sense and the original direction of participant voices (which are necessarily constrained by individual experience). I suggest that, like most phenomenological studies, the analysis provided is not necessarily replicable by a different researcher attempting to use the same material, but should be judged rather on the criteria of 'is it a reasonable interpretation of the material according to participants' (interpretive validity (see Sandelowski 2000)). In this manner, I believe that the analysis will 'ring true' to the "thoughtful clinician" (Thorne, Reimer Kirkham & O'Flynn-Magee 2004, p. 17).

4.5 Research Parameters

The strengths of this research are its iterative nature, its intent to investigate and describe an unexplored phenomena and its intent to develop theory from the data: utilising the "value of qualitative inquiry's 'toolbox' that enables researchers to develop concepts" (Morse 1984, cited Marshall & Rossman 2006, p. 208). The utilisation of more than one qualitative method adds to the rigour of the research, as do the iterative, longitudinal process of analysis, extensive use of observation (ethnographic approach) and continuous 'member checks'. The influence of grounded theory in avoiding fixed pre-established rules, and rather maintaining a readiness to adapt methods and procedures according to data/research leadings, is clear. Its recognition of the inherent likelihood of multiple perspectives (Strauss & Corbin 1994, p. 80) and "troublesome uncertainties" (Gubrium & Holstein 1997, p. 13) adds to its reflexivity: "[i]n a grounded theory approach these are to be expected and are not hidden or masked" (Hansen, E 2001, p. 103). Equally, this research explicitly acknowledges the role of the researcher in the research process – in interaction with other research participants and co-creation of data, analysis and even (to some extent) theory.

It is important to note, that like all research, this project has its parameters. In particular, potential those of purely qualitative research - specifically concerns with potential generalisability, bias (researcher and sample), and credibility - must be addressed. In applied health research, "qualitative research goes 'against the grain' of the dominant quantitative research paradigm in the health sciences" (Eakin and Mykhalovskiy 2005, cited Hunt 2009, p. 1291). As a person whose initial health training was within a positivist paradigm, I personally had early doubts about the value of a solely qualitative project within the research 'training ground' of my PhD candidature. However it became apparent that not only was there a serious question to be explored, but that it deserved the intensity of interpretive focus that a purely qualitative project could provide.

The constraints of candidature (limited budget and personnel) also curtailed my capacity to access and process both quantitative and qualitative data. By shifting to a solely qualitative methodology but with multiple methods, this study addresses Silverman's 1998 concern about some nursing research methodology, which Nelson and McGillion summarize as a tendency to concentrate around interviews, "as opposed to observation and mixed approaches" (Nelson & McGillion 2004, p. 633). This research utilises a range of interpretive data collection methods, but avoids the potential 'quagmire' or 'method slurring' of mixed methods (Baker, Wuest & Stern 1992; Barbour 2006). It seeks validity in qualitative terms, where " 'valid' is a label applied to an interpretation or

description with which one agrees", rather than (as in a quantitative setting) where validity is held to reflect 'reality' (Sale, Lohfeld & Brazil 2002). It thus aspires to what Ezzy categorises as the 'political model of rigour' in qualitative research: where positionality is declared and critical reflexiveness maintained, where a voice is provided for a sector presently "silenced or marginalised in traditional political processes", where research, political and participant communities becomes essential arbiters of quality, and where the results and benefits of research are returned to participants (Ezzy 2002, p. 56). In common with many feminist, postmodern and hermeneutic interpretations, this research rejects the notion of " 'one true, unbiased' interpretation", and recognises that "all research represents particular political interests and theoretical influences" (Ezzy 2002, p. 57). By acknowledging my biases, and engaging with them directly, I attempt to maintain the research's transparency and thus credibility.

Bias is a related concern in qualitative research, which I see as having two aspects: researcher bias (inherent value judgements which colour the data collection and analysis) and sample bias (where a purposive sample is insufficiently diverse as to gain a variety of material). Researcher bias is a particular risk within single person research projects. Where the data is collected - indeed co-created with participants - by one sole researcher, the capacity for bias of that data is increased. Equally, where only one person reads and analyses the data, the prospects of an idiosyncratic interpretation grows. However, this is where the integrity of the researcher is paramount, in designing, executing and communicating the research as best possible within the realities of social sciences PhD candidature. The research design is constructed to enforce reflexivity: with constant revision and self-questioning throughout the life of the project. Sections of data have been shared with supervisors at various stages, and with participants in a kind of constant 'member-checking'. The use of literature as a further source of data throughout the project, rather than solely as a determiner of '*a priori*' categories, has also pushed me to question the content and direction of the analysis. The research design is thus calculated to reduce individual bias. However I acknowledge that, in the end, the construction and interpretation of this material is mine and mine alone. It is impossible to exclude bias entirely, however by making my biases explicit, I alert the reader to potential tendencies.

Bias within the sample is another potential criticism. The self-selection of participants (volunteering in response to research advertisements) rather than randomized sampling is sometimes of concern, and the relatively small sample sizes of qualitative research can disconcert some researchers. Consistent with qualitative research, this project's sample size is small (26 participants). However the data is rich, due to the time spent in observation and informal

conversation, as well as lengthy (and in some cases more than single) interviews. I believe that this sample represents an unusual group of health professionals, in that they have self-selected to be involved in a research project, and may therefore be more committed to development of their professions, to self-reflective practice, or other properties of research. They may also be inherently more interested in chronic conditions healthcare than other healthcare professionals, and thus have different views. Indeed, with the relatively small numbers of rural health workers in a relatively small Australian state, self-selection could be conceived to create inevitable biases (towards squeaky wheels, people with axes to grind, research interested professionals, and so on).

A particular point of interest is that rurality did not occur as a major theme for participants. While general issues of rurality (such as access to services, transport concerns where patients were unable to drive, blurred roles and cultural safety, across socio-economic cultural divides as well as ethnicity) were mentioned in passing (consolidating existing rural health research as discussed in Chapter One), it appeared that rurality was not a major theme in chronic conditions healthcare. This was despite directly probing for issues of rurality specific to chronic conditions (see Interview Guides, Appendix 2). Given the lack of prominence of rurality as a theme for participants, this thesis does not therefore focus on issues of rurality.

It was also noteworthy that no participant within the sample specified residential care (nursing home work) as their primary occupation. Nursing homes are a major provider of rural nursing work, and increasingly of healthcare provision in the community, as well as in residential aged care facilities. While several participants discussed previous nursing home work, some participants worked with long-staying patients in hospital, and one participant was an employee of a nursing home as well as of the general practice through which she was referred to the research, it would have been useful to directly target residential facilities for research recruitment. Nurses (enrolled and registered) within residential facilities may be able to provide additional windows into long-term conditions work (such as with frail aged or people with dementia).

Nevertheless, inclusion of multiple people within some work sites, multiple worksites, and multiple health disciplines, gives me confidence that a broad range of views and interests have been canvassed. Through 'snowball sampling' from earlier respondents, participants who did not originally self-identify as interested in talking about chronic conditions healthcare, and who were not originally interested in participating in the research were obtained. Whilst not all the material gathered has been presented (and material presented necessarily supports the research argument), that does not mean that it is an inappropriate interpretation of the material. The research is

qualitative, and not designed to be representative of the workforce as a whole, but rather to give indicators of potentially relevant areas which need further investigation.

Glaser acknowledges, "we do not have to discover all new categories… in order to generate a grounded theory" (Glaser 1978, cited Ezzy 2002, p. 94). Accordingly, some health workers will always be more engaged with chronic conditions healthcare (and with research) than others, and this research gives a picture of those clinicians, portraying clinicians with specialist chronic conditions healthcare strengths which can be potentially encouraged in other contexts. Other clinicians within the sample simply saw chronic conditions healthcare as one part of a broader work context: their responses and understandings are necessarily different, and are also presented.

As with most qualitative research, findings from this study cannot be automatically generalized (replicated) in the traditional positivistic sense, that is, considered strictly representative of the Australian rural health workforce as a whole. Qualitative research does not traditionally prioritise generalisability, rather "the examination of subjective experience in depth" (Ezzy 2002, p. 148) as a thematic indicator for possible issues in other contexts. However, given that the topic of the research is not unfamiliar or exotic, and that to some extent this is a "study of the typical" (Schofield, JW 2002 [1990]), the opportunity to make 'naturalistic generalizations' is enhanced. Schofield describes naturalistic generalization as a process of taking findings from one study and applying them to the understanding of similar situations: "through experience individuals come to be able to use both explicit comparisons between situations and tacit knowledge of those same situations to form useful naturalistic generalizations" (Schofield, JW 2002 [1990], p. 179). She suggests techniques for studying "the typical, the common, and the ordinary … included choosing study sites on the basis of typicality and conducting multisite studies" (Schofield, JW 2002 [1990], p. 199), both of which criteria are satisfied by this research.

4.6 Research Ethics

In this section I address both the practicalities of ethical issues within this research, and also provide a window into the research journey; in order to address Coffey's concern that "there has been little systematic attempt to reflect upon … experiences in and emotions [within fieldwork]"(cited Dickson-Swift et al. 2006, p. 61).

The project was approved on 19th May 2008 (H0010036), through a minimal risk application to the Human Research Ethics Committee (Tasmania) Network. A subsequent amendment, to

increase the number of observations and change the chief investigator, was approved 6th May 2009, and the final ethics report submitted in May 2013. When I approached Ambulance Tasmania (DHHS) to distribute the research invitation through their networks, they requested a copies of the Health Professional and Patient Information and Consent Forms (see Appendix 1A-E). These were then approved by DHHS contracts and agreements legal support on 16th April 2010, and distributed as requested.

I see some ethical issues as more substantive to rural health research and also common to qualitative research; namely participant de/identification, and researcher 'blurry boundary' issues (see discussion below). De/identification of participants in small population research is always a consideration, and in a rural context is particularly relevant. Rural health professionals are often well aware that they cannot be guaranteed anonymity within their own region. For example, if a participant is the only specialist in a particular field (allied health, nursing or medical specialty) in their region, and their gender or region is specified in research writing, then this may be more than sufficient for other healthcare professionals and patients in that region to identify an individual. Tasmania as a whole is quite small (population less than half a million), and there are only three geographical regions within health department and general practice organisations. It was thus possible that participant research readers might be able to identify each other, and it was vital I made this clear in discussions prior to obtaining consent.

Equally, ethics in rural situations are slightly different to those of more populous areas. Crowden argues for a 'distinct rural ethics': to "capture the ethical dimensions of rural situation where access, dual or overlapping relationships, confidentially, cultural safety, small community clinician stress, and/or team practice" must be considered across all relevant professions (Crowden 2008) p65. I suggest that this notion of a distinct rural healthcare practice ethics applies equally to rural research. However, I also consider it true that a

> … more nuanced view of consent means moving away from the assumption that every respondent desires complete confidentiality, and instead recognizing that a research participant might want to receive recognition for some or all of what he or she contributes (Kaiser 2009, p. 1638).

Kilpatrick et al, for example, employ consent forms which ask participants to acknowledge that it is possible that they could be identifiable in written research outputs in small population areas (Kilpatrick et al. 2008). Pride, or in this case, rural pride, may well motivate some participants to want to claim identity for their work and their discussions of that work.

Nevertheless, the relaying of personal opinions about work for research purposes must always be assumed to carry a certain amount of risk, as identification of individual opinions about a workplace or work practices may give rise to misunderstandings or concerns. In this research, I considered de-identification and/or confidentiality of participants reasonably important, given that it is possible that employers and patients of participants might be reading research results. I was also concerned it could be difficult for some participants to speak freely about work unless guaranteed complete anonymity. However, as the topic of my research is fairly abstract and not particularly intimate, I did not expect participants to be very likely to contribute material which could be considered particularly contentious or potentially self-damaging. I therefore offered to guarantee confidentiality to all participants, but discussed the option of self-identifying if a participant wished.

No participant requested full identification, although some 'didn't mind either way'. In writing up this thesis, I have chosen to anonymise data for all those who requested it. I do not identify in which region which participant is based, and I have given most participants pseudonyms (other than those who wished to remain identifiable). I decided that, as no participant preferred full identification, I would give only first name pseudonyms. In some cases I de-identify by changing the gender of the participant (where this does not appear to influence the particular material being discussed), in particular where the four male participants are concerned. This level of de-identification means that where a participant wished to be identifiable, readers who know a participant's name, profession and gender should be able to identify those participants.

Another common ethical subject in qualitative research is that of researcher boundaries, including such concerns as 'going native' (compared with ethnography or anthropology) and researching known participants. In this research situation where I, as the researcher, am a rural resident, and researching within my own region as well as the rest of the state, the question is not so much about 'going native' as about 'insider/outsider' research, and /or 'blurry boundaries': ('researcher-friend, researcher-therapist, professional boundaries') (Dickson-Swift et al. 2006). Prior to PhD fieldwork, I thus re-considered whether I was comfortable to research friends, colleagues and acquaintances; as well as to research within my own region as well as the other two regions within Tasmania. I concluded that it was important to satisfy the purposive sampling criteria that participants be diverse and thus sourced from all three Tasmanian regions; and that it was also important to me not to exclude people known to me who were interested in participating. I thus did earlier fieldwork closer to home, to some extent 'piloting' my methods on known

participants. I simultaneously commenced recruiting Tasmania wide, and in the end, had only two participants I had known prior to recruitment.

As in my Honours research, I thus had the opportunities to be both (partial) insider and outsider, with the kind of objectivity of 'the stranger' (Simmel 1971[1908]). While I am not a healthcare professional, my time as a medical student means that observation in clinical contexts is not wholly foreign to me, although my aims in this kind of observation were very different. Rather than knowledge- or skill- acquisition, I was focusing on the behaviours and interactions of the clinician: rather than questioning or attempting to understand therapeutic detail, in the earlier stages of fieldwork I was focused on broader consultation content (acute, preventative, chronic conditions related, and so on), and in later stages of fieldwork attempting to note possible shifts between types of clinician logic alongside consultation content (reactive or planned, adherence to any particular modes on chronic conditions healthcare, and so on).

I observed and interviewed 'without judgement' as much as possible, a task made easier by the variety of contexts and professions which I observed and interviewed. Although originally unfamiliar with all issues of chronic conditions healthcare for almost every participant, as chronic conditions healthcare became more familiar I nevertheless negotiated senses of 'sameness and difference' (Valentine 2002), and of 'positioning' (McKay 2002) with each participant. I quickly became comfortable with the fieldwork and writing processes I enacted, yet I still felt still slightly excluded: "[w]riting up the research seems to be the key act of exclusion that recreates the visitor/friends divide into research/subjects" (McKay 2002).

Considering my own boundaries as a researcher was thus, to some extent, more difficult than the considerations of geographical boundaries. Following Denzin (1984), Dickson-Smith summarises:

> [i]f 'emotionality does lie at the intersection of the person and society', then it follows that emotions are a central part of social research. As Denzin (1984: x) asserts, 'to be human is to be emotional'. As qualitative researchers, our goal is to see the world through someone else's eyes, using ourselves as a research instrument; it thus follows that we must experience our research 'both intellectually and emotionally' (Gilbert, cited Dickson-Swift et al. 2009, pp. 61-62).

In congruence with issues of closeness with known participants, there is also an intimacy generated in the process of doing an in-depth interview of a stranger. I have been careful to test ideas and even (where possible) writing excerpts, with appropriate participants and other non-participant (but representative clinicians) as a form of 'member checking' (see Thorne 2008, p. 159). This is part of the reflexivity within this research. Ethically, it is also important that the

fieldwork material (including the video data) remains available to future researchers for alternative interpretations.

McKay notes that in research, "people will ask you to explain who you are and why your research questions are important to you" (McKay 2002, p. 187). I appreciated both being asked this, and also being assured by participants the research was of interest and importance to them. Tracy emphasised this half way through the fieldwork:

> Tracy: I think it's good to be reflective, on what you feel like you're doing, what you feel like you're doing well. How things affect your personal life as well. Cos [sic] often when you talk about work, you don't cover what, how it's balancing with your personal life. [dietician, 6-5-10 p30]

Elise also reminded me that the research had purposes beyond the life of the PhD:

> Elise: I'm getting more a sense of – what brings people to chronic condition management, is there something unique about those people, or is it something unique about their experience, or what is it about people that choose, and we *do*, you know - you get people that are adrenalin junkies that only ever work in ICU and DEM, well, what is it about *this* group of people? Are they unique and distinct as well? And should we be able to pitch and target those, the same as we pitch and target those [ICU and DEM workers]?" [diabetes educator, 18-4-11 p47]

Elise also stated that participating in the research had "it's something I thought about for several days after" [Elise, personal communication (research memo during phone call), 27-6-11]. This, to me, was a clear demonstration of the transformative power of participating in this research.

In the end, I had to trust that my own efforts to maintain the validity, and the ethical 'worth' of the project, were sufficient.

> Between the extremes of absolute truth and no truth is the lived reality of half worked-through truths that shape our daily lives (Ezzy 2002, p. 2).

By working to convey a sense of the complexity of the research participants' professional work and lives, this thesis contributes to a clearer perspective on the reality of doing chronic conditions healthcare.

4.7 Summary

In Chapter Four I examined the methodological influences and conceptual frameworks which shaped the doing of my research. Multiple methods (observation, semi-structured interviews and filmwork [consultation videos and video-triggered interviews]) enabled comprehensive coverage of the experiences of rural healthcare professionals doing things that they consider to be part of chronic conditions healthcare. Ethical issues in doing rural research, and particular to rural health,

were also explored. This chapter, as a conclusion to the introductory section, forms the foundation for Section Two (Chapters Five to Seven), which present findings and analysis.

PART TWO: FINDINGS AND ANALYSIS

5 Chronic Conditions Healthcare: Participant Understandings

5.1 Introduction

Chapters Five, Six and Seven present findings and analysis. Chapter Five examines some definitions of chronic conditions healthcare from participant perspectives, Chapter Six looks at specific techniques and tactics which participants use to do chronic conditions healthcare, and Chapter Seven exploring external factors which influence how participants do chronic conditions healthcare.

In this chapter, I explore what it is that participants think comprises chronic conditions healthcare. Chapter Five demonstrates that healthcare professionals rarely define chronic conditions healthcare in the same way, where they are able to define it at all, and that a definition of chronic conditions healthcare was less important to them than an 'understanding' of the nature of chronic conditions healthcare.

During fieldwork, participants were prompted to make various attempts to define chronic conditions healthcare, both to me as the researcher, and to themselves. Gradually, it became clear a shared language for chronic conditions healthcare, across professions and levels of healthcare, does not yet exist. However, commonalities in what clinicians perceive to be relevant to chronic conditions healthcare are discernible, and will be discussed. This chapter initially presents participants' attempts to define chronic conditions healthcare as a list of "*versions* … that are equally socio-material in kind but occur (emerge, come about) in different circumstances (settings, practices, situations)" (Mol 2012, p. 126).

Participants attempt to 'out' chronic conditions healthcare by quantifying, by practice-based examples, and by contrasting with other kinds of healthcare work. Participants' experiences of other kinds of healthcare work, which they considered (and I observed) to have general relevance

to chronic conditions, are then canvassed. Chapter Five describes how other disciplines provide ways of doing chronic conditions healthcare, with specific techniques described in Chapter Six.

5.2 Defining 'Chronic Conditions Healthcare'

It became clear early in the fieldwork that asking about chronic conditions healthcare involved broaching the subject for the first time for some participants. For most, chronic conditions healthcare was not a clear category, although 'chronic conditions' was. What I was asking about (which at that time I phrased as 'chronic conditions work') was a 'slippery' concept. Most participants simply did not separate out their chronic conditions healthcare from other kinds of work within their practice, as exemplified by Maureen:

> Maureen: I guess I just don't see chronic conditions as 'out there'. I don't, I don't really split it off in my work, except when I think about running a specific, say a Stanford program, which is sort of badged as chronic disease self-management. Basically, most of my clients are going to have chronic health conditions. [late career community physiotherapist, 3-5-10 p24]

Typically, asking health professionals to specifically discuss their work regarding chronic conditions took some probing: discussion of what they personally would and wouldn't include in a definition of chronic conditions healthcare. Different professionals had different views, different disciplines had different views, and different individuals had different experiences of what it means to work on chronic conditions (with either individuals or populations). Definitions of chronic conditions healthcare only emerged after considerable probing, a kind of "collaborative construction" within a process of active interviewing (Holstein 1995, p. 59).

Healthcare professional participants typically initially conflated 'chronic conditions' with 'chronic conditions healthcare', and generally provided a definition of both simultaneously. For some participants, asking about chronic conditions healthcare involved co-constructing an understanding of chronic conditions healthcare as a separate category within clinical practice for the first time. While most participants could explain what was involved (for example, overarching principles) in other subspecialties (for example, midwifery, aboriginal health, palliative care; across primary, secondary and tertiary healthcare), many of their present definitions of chronic conditions healthcare were based on, and limited to, individual and specific contexts. In other words, they knew experientially what it was that they were doing, but struggled to 'name it up' other than in disease-specific ways. A group interview in a rural hospital with Beth, Sally and Moira elicited the following (fairly typical) initial level of understanding:

> Sally: Chronic conditions is ongoing care for people, as in they've got a long term prognosis and they just keep coming in for that condition and you treat to a certain

> level and then the condition is still there and keeps coming back. [Beth, Sally and Moira, DoN/RN, EN, EN, 5-6-10 p2]

The members of this small group then proceeded to give multiple examples of specific diseases, debating which were and weren't chronic conditions. 'Chronic conditions' were a clear category, within which diseases could be excluded or included. However 'chronic conditions healthcare', in their eyes, was simply ongoing care, indivisible from care for any other clinical purpose. While that particular interview took place in a small rural hospital, community-based participants similarly equated defining 'chronic conditions' with defining 'chronic conditions healthcare'.

I found myself attempting to capture people's definitions of chronic conditions healthcare, amidst persistent conceptual shifts: even on direct questioning, participants reverted to trying to define 'chronic conditions' rather than 'chronic conditions healthcare'. They also defined their chronic conditions healthcare according to their definition of and professional exposure to chronic conditions: those who had done chronic conditions specific training (eg diabetes educator training or chronic conditions self-management support training) had much clearer understandings of what they were trying to do, even if they were not explicitly using acquired chronic conditions techniques. Within the observations and interviews, I began to explore - ask explicitly, probe indirectly – participant definitions of chronic conditions healthcare. I discuss findings from this in Section 5.2.1-3 below, and clinicians' more tangential descriptions of chronic conditions healthcare, via discussion of other healthcare sub-disciplines in Section 5.3. I will discuss how such conceptualisations inform clinicians' approaches to practice in Chapter Six.

5.2.1 Defining through quantifying

As noted, most participants did not have an immediate answer when I asked about their definition of chronic conditions healthcare; yet when I asked participants how *much* of their work was chronic conditions related, there was almost always a clear answer, usually stating a high percentage. The fact that most were able to quantify their chronic conditions related work implied they did distinguish it from other forms of work, as in these examples:

> Tracy: Oh, seventy to eighty percent. [dietician, 6-5-10 p7]
>
> Martin: Most of it. […] I mean yesterday, it was pretty well all of it. [community health nurse/midwife, interview with partner (also a health worker and research participant) present, 21-9-10 p15]
>
> Dunc: The chronic business? I think it would form a fairly large percentage of our workload, I think. [paramedic, 16-6-10 p23]
>
> Kathleen: [sigh]. Probably sixty, seventy percent. Well, it does, depends on how you define it. Today could have been 100 percent. [community nurse, 11-6-09 p2]

An occupational therapist gave a more detailed version:

> Mike: Oh… in man-hours terms, probably sixty percent. In numbers of referrals terms, probably more like sort of thirty percent. Just that the chronic ones chew up more time cos [sic] you see them more often, type thing. [occupational therapist, 3-5-10 p8]

It appeared easier for healthcare professionals to discuss how *much* of their work was chronic conditions related, before discussing their personal definitions of, and approaches to, chronic conditions healthcare. As a result, I began asking how much of their work was chronic conditions related before asking for a definition.

Mike drew a clear distinction between the volume of work generated by people with chronic conditions, and the actual numbers of referrals. People with chronic conditions were only thirty percent of his "numbers of referrals", but they generated sixty percent of his workload. Mike's answer emphasises the importance of quantifying amounts of work generated, as well as actual referral numbers, in order to determine appropriate resource allocation. He highlights the importance of seeking context-relevant definitions of chronic conditions healthcare.

5.2.2 Defining through practice-based examples

Most commonly, research participants defined chronic conditions healthcare through use of examples. While the examples and definitions themselves are interesting, and some follow below, it is the use of examples itself, which suggests these health professionals understand chronic conditions healthcare on the basis of practice. It was easier for most to describe what they did, than to refer to specific chronic conditions funding models or frameworks they were trained in.

Josephine was one of the earliest respondents for this research, from what I found a surprising (and what emerged as an unusual) context: a medical day unit, largely an oncology day unit, accessed by walking through the rural hospital. Being a day unit impacted on the amount and style of chronic conditions healthcare she did, yet she characterized most of what she did as chronic:

> Josephine: Oh, about ninety percent is chronic. Really, because, one... when we get someone referred to us, **they're usually going to be with us for an extended period of time**. And I suppose it depends on what your connotations of chronic are. **To me, it's more about the fact that they're going to be living with a disease, six months, twelve months, two years or whatever timeframe is left for them. Yeah**. [late career hospital medical day unit, Director of Nursing (DoN), 25-9-08, p7-8, emphasis added]

Josephine's definition of chronic was based on her perception that people were living with a disease for an extended period of time – even though other health professionals, and lay people, might not define "six months, twelve months, two years or whatever" as long-term. Asking

someone to quantify his or her chronic conditions healthcare had given a practice-based example of a different definition of extended temporality, and therefore of chronic conditions healthcare.

Dunc used colourful practice examples to explain his experience as a rural paramedic, creating a picture more than a definition of chronic conditions healthcare:

> Dunc: You know, you get this bloody old farmer that I got the other night, and he has got a chronic condition, but he's not taken the time to manage his own health at home. He has not taken the time to have regular check-ups and finger up the clacker for the prostate and regular blood pressure - like he was in AF [atrial fibrillation] as well, and he didn't tell me that he had that previously, but he definitely had it before, on his notes. But people forget what they have been treated for, and it's bloody, ah, it's annoying. But his condition the other night was secondary to a chronic condition. Yep, due to an arrhythmia. [late career paramedic, 16-6-10 p24]

He went on to discuss giving smoking cessation advice given to another patient. He thus implicitly included both acute management and health promotion within his definition of chronic conditions healthcare. Practice-based definitions - things he felt timely and necessary to do for patients with chronic conditions - demonstrated what it was that he considered important within a spectrum of chronic conditions healthcare.

Other participants provided similarly complex pictures of chronic conditions healthcare, problematising and extending their examples. Tracy had a quick answer when asked 'how much of your workload is chronic conditions related?': "Oh, seventy to eighty percent" [6-5-10 p7]. However her immediate codicil was to complicate this apparently clear understanding:

> Tracy: But then, they're not necessarily the normal chronic type things. […] The normal ones I would probably consider diabetes, which we no longer do. Cystic fibrosis kids are mostly seen at [regional centre] now. Heart disease, which is only covered by cardiac rehab […]. The chronic ones really are the disability ones, I feel – the ones that are on the PEG feeds [percutaneous endoscopic gastrostomy] - got a few kids on tube feeds as well, or PEG feeds. [early career dietician, 6-5-10 p8].

She thus made a distinction between 'normal' chronic conditions (diabetes, cystic fibrosis, heart disease) which other dieticians saw, and other less commonly presenting chronic conditions (adult disabilities, childhood disabilities), which she saw. These included non-specific conditions like 'failure to thrive', obesity with complications like fatty liver or high cholesterol, chronic constipation, childhood obesity, and 'the peg kids' - children with conditions like cerebral palsy and high level autism who were incapable of ingesting normal diets and thus on peg feeds [Tracy, early career dietician, 6-5-10 p10].

Tracy's dietician role was not to deal with 'normal' chronic conditions, which were dealt with by disease-specific programs elsewhere in the hospital and the community, but rather with 'others'. While her definition of 'normal chronic conditions' was about common chronic diseases, she had refined her definition of chronic conditions healthcare through examples of less commonplace disorders. She believed her work to be in roughly three equal timed areas: working with outpatients, doing administration, and working with home nutrition patients. While most of the home nutrition work was generated by people with chronic conditions, some of the administrative work was generated by patients with chronic conditions, and some of the outpatients work was with people with chronic conditions. For Tracy, chronic conditions healthcare occurred in all of her work content (outpatients, admin and home nutrition), and was therefore best communicated to me via practice examples: differentiated into 'normal chronic conditions' and 'others'.

Mike, an occupational therapist, also used examples of chronic conditions, and divided his practice into three groups he considered typical for public community-based OTs. His categories were based on the numbers of contact visits over long durations. The first group would require one to three visits, and "may or may not have a chronic condition, they might be COPD [chronic obstructive pulmonary disease] or something like that" [Mike, mid-career occupational therapist, 3-5-10 p4-5]. This group also included the frail aged.

The second were "the people who'll you see a fair few times but for a limited period of time" (for example, those admitted through palliative care). The third were what he called as "our chronic-y ones", […] "which are just the really long and on-going ones" [Mike, mid-career occupational therapist, 3-5-10 p4-5]:

> Mike: Our chronic guys tend to be - who we see a *lot* - would tend to be more the spinal condition guys, and the neurological guys, things like that. So people that we see on a really long, prolonged basis. [mid-career occupational therapist, 3-5-10 p3-4]

Mike provided examples of the third group, in particular "the spinal guys", listing multiple conditions (spinal bifida, neurological conditions including muscular dystrophies, multiple sclerosis, "some of the ataxias, the cerebral palsy things") with whom he expected to have longitudinal involvement (twenty to forty year prognoses). He described a pattern of a few visits early after referral, then "get[ing] uninvolved for a couple of years", then back in again [Mike, mid-career occupational therapist, 3-5-10 p4-5]. Again, his definitions were dependent on specific practice examples; implying that his definitions of chronic conditions healthcare could best be tied down by specific examples, rather than categories.

A number of participants did not have a clear perception of chronic conditions healthcare, demonstrating the general invisibility of chronic conditions healthcare for participants. They generally evolved their definitions over the course of a day spent together, and also within the interview itself. This was not unexpected, given the transformational intent and awareness within the research design, in that bringing attention to a specific issue is often transformative in itself. Despite having volunteered for research into chronic conditions work, they often initially categorised some work as 'not chronic conditions related', but on reflection or examination shifted their positions.

It appeared that, for some participants, chronic conditions healthcare was so normal a part of everyday work, and so interspersed within many kinds of practice, it was almost invisible to the healthcare workers themselves. Work that they initially categorised as 'not chronic conditions healthcare', on examination, they might re-categorise as chronic conditions-related. The following example is characteristic of this kind of invisible, then evolving definition. Kathleen, a community nurse, initially categorised only one episode within that day's work as chronic conditions healthcare [Observation Notes, 11-6-2009]. In our interview at the end of the day, she first queried my definition of chronic (despite us having just spent the day together, including drive-time between clients where discussion of chronic conditions healthcare was frequent), and re-calibrated her own definition 'on the hop' throughout the interview:

Anna: Ok, so we've just had almost a whole day's worth of clinical time. Was that a fairly typical day?

Kathleen: Yep.

Anna: How much of that would you have called chronic conditions healthcare, and how much non-chronic?

Kathleen: Ooh… what are you calling chronic? Well, really, the second gentleman was the chronic conditions healthcare.

Anna: So that was Donald. [a long-term 'disability support package' client]

Kathleen: Yes. The first lady had a fairly long but still fairly acute wound. Now she does have an underlying chronic cancer, so I guess… and that's why we're keeping her on the books. So really I guess if you include her, well, fifty percent of what we saw today. And then again, Mollie, supposedly cured of her cancer, but still with some fairly chronic, longterm, or longer-term health issues associated with that surgery for that cancer. […] And then Stewart. [further explanation concluding that both these patients had chronic conditions which required attention, as well as their wounds] [mid-career community nurse, 11-6-09 p1]

As Katherine reflected on the day's work, she re-categorised all four patients as generating chronic conditions healthcare which she had spent significant time on, despite initially only

categorising one as 'chronic'. Although all the patients Kathleen had visited that day were listed for wound-care, equally they all had chronic conditions, which precipitated either (a) the wound itself, or (b) a requirement for more extensive consultation time to deal with underlying issues behind the wound. Each visit involved at least half the consultation time dealing with broader physical and mental health issues brought on by chronic conditions underlying the acute wound-care needs, and during our interview she became more conscious of this. She considered what happened with Stewart, her final patient for the day, a regular occurrence:

> Kathleen: He's got some chronic pain issues, he's got some chronic health issues.
>
> Anna: And the wound care was the presenting reason?
>
> Kathleen: Yep. And that's quite often what happens. We'll get a referral for a so-called acute care episode, as a result of him having had some acute care in hospital, some surgery, but then, when you dig a bit deeper, you find that there's all these other associated issues - that they're living with. Which is *nothing* to do with what we may have been referred to them for. […] And it didn't take me long to do his wound-care did it? [mid-career community nurse, 11-6-09 p1, original emphasis]

Acute wound-care was the presenting reason for admission to community nursing service in three of the four cases that day; however the bulk of the day's clinical time was spent in discussion of and support for chronic conditions. Yet Kathleen initially categorised only *one* of the day's projected four clientele as 'chronic'. The invisibility of chronic conditions healthcare for healthcare workers is thus (to some extent) perpetuated by clinicians, for example in the lack of clarity within referrals about 'big picture' as well as acute issues.

5.2.3 Defining by contrasting

The next most prominent way that participants defined chronic conditions healthcare was through contrasting different types of work (comparing different approaches, comparing different professions, or specifying "what it's not"). In this way they sought more to illuminate the nature of chronic conditions healthcare, rather than to define it. In many cases this involved contrasting the type of work done, to highlight aspects of the nature of chronic conditions healthcare significant to the person speaking. Some examples follow, to illustrate the practices and factors participants considered when attempting to define chronic conditions healthcare.

Different nature of long-term professional-patient relationships

The most common comparison was to acute work, as with self-confessed former "adrenaline junkie" Heather. For Heather, chronic conditions healthcare was about long-term relationships and being "involved" as part of a longer story, rather than having a bit part in a shorter, more dramatic story. She suggested the relationship between health professional and patient was very different in acute work and chronic:

Heather: You actually get to know a side of the person that you *don't* in acute conditions. In acute conditions, the person comes up in, with a baby or a cough, or whatever. And you deal with that, you know, cough gets better, you probably never going to see the person again. Until their next cough or whatever. […] But it [chronic conditions healthcare] is, it's being part of a story, and it's actually very... I think rewarding. Which is interesting, because many years ago, *I* wanted to do anaesthetics, or pathology, or emergency medicine, which you see someone and they *go*. [laughs] It's a *very*, short story. I didn't *want* to be involved in the long term, and it's surprised me that... I'd like that part of it now. [mid-career GP, 23-9-08 VTIi p13-14]

Josephine also compared chronic work to acute, characterizing symptomatic responses as acute work and ongoing treatment as chronic. Describing her oncology outpatient clinic, she categorized most of her work as chronic:

Josephine: Some of it's acute, in the terms of what's going on at that time for someone. And like, you'll get, like acute leukaemics or high-growth tumours and it's very acute, in that period. […] But then, once you've managed that, and the patient's recovered from that phase, then generally they still need to be involved, in active treatment or certainly on-going... supervision, monitoring, things like that, if nothing else. [late career hospital medical day unit, Director of Nursing (DoN), 25-9-08, p7-8]

Where participants compared acute with chronic work, the *nature* of the relationship in long-term conditions work was highlighted. It was not simply the ongoing extension of a relationship that appeared important, but the ways in which this changed the dynamic of the professional-patient relationship, and therefore way of working, which was emphasized. Maureen suggested that the different nature of a continued relationship with a patient made that patient more interested in proffered health advice:

Maureen: Like, you *know* a lot about their background – so… you remember stuff. When you know someone well enough to remember what's been happening with their medical history, or even just the fact that they were on holiday in Fiji or whatever; they um, they treat you a bit differently. […] And they're more interested in what you're got to say. [late career community physiotherapist, 3-5-10 p16-17]

For many of the participants, the interest in doing chronic conditions healthcare was not so much an interest in chronic conditions themselves, but rather in personal relationships, ongoing stories, and different nature of the professional-patient relationship within long-term conditions. Some described maintaining interest in each person through sharing longitudinal stories (life events or narratives intertwined with the illness narrative which brought the clinician and patient in contact), as discussed above. However Maree summarised it succinctly:

Maree: Yeah, it's the relationship, the connection. [late career psychologist, 9-05-12 p12]

Different attitude to chronic conditions healthcare

When asked a direct question, participants usually agreed that chronic conditions healthcare was different to acute or preventative healthcare work. However, they sometimes struggled to specify how, as in this group interview:

Beth: Cos I think it is more to do with relieving symptoms, and ways to cope more. Have the best quality of life they can.

Sally: Working out a pathway which is a good result for them, to cope with their condition.

Moira: Because we're in a rural setting, I believe that we don't have the opportunities like the Royal have. [DoN/RN, EN, EN, 5-6-10 p3-4]

These three nurses perceived that chronic conditions healthcare was different to other kinds of healthcare work, and that the rural setting affected the doing of such work, yet they struggled to specify what it was that was different. Their comments contrast with those of Kate, a pharmacist, who compared chronic conditions healthcare with acute work, but suggested that the difference was in how much and what kind of information you presented to a patient, and what ways you reinforced or operationalized (made into practical goals) such information. She perceived the attitude of the health professional, in particular in recognising that they were dealing with a chronic condition patient, as crucial to what kind of information was presented and when:

Kate: I guess it's mainly… the overreaching need to know that this person is going to have to maintain this behaviour for a long period, for the rest of their lives. [mid-career pharmacist, 5-5-11, p7]

Whilst only explicitly described by some participants, and more often implied as in the group interview above, this kind of attitudinal shift was a clear distinction, which differentiated chronic conditions healthcare from other kinds of healthcare work. Most participants discussed a shift in attitude as much as a shift in clinical techniques. Techniques used are further discussed in Chapter Six.

Specific chronic conditions languages

Those participants who did have a clear definition of chronic conditions healthcare had generally done specific chronic conditions focused training (for example diabetes education or chronic conditions self-management support training), and incorporated at least the 'attitudes' of this, if not actual daily practice, into their work (Brenda, Isobel, Maree, Kate, Elise). They used characteristic specific languages and frameworks, sometimes within definitions of chronic conditions healthcare, as well as defining chronic conditions healthcare by differentiating it from other kinds of work. Maree's definition was typical of this group:

Maree: I guess I would define it as… **enabling** might not be the right word, but **supporting** people to be able to be much better **self-managers**. So being able to - rather than being a victim to their chronic illness - being much more **active** in managing their chronic condition. [late career psychologist, 9-05-12 p4, key chronic conditions self-management words in bold]

Isobel described chronic conditions healthcare as her passion, and defined it as

> Isobel: [W]orking with people to identify what their idea is - of what's happening to them, right now." [Isobel, mid-career community health nurse/health promotions worker, 6-4-09 p3].

She was particularly motivated by self-management support models, and her experience of using them with patients:

> Isobel: I suppose it's… when I think about things like the Flinders model, and the dynamic approach to people, and health coaching. And how things, a *light* goes on in people's heads, when you promote, you know, self-management. People *get* it. […] Something really special happens when they get it, when they realise that I'm not going to tell them what to do. [mid-career community health nurse/health promotions worker, 6-4-09 p5]

She then discussed a patient we had visited earlier that day, who "would still like me to tell her what to do." [Isobel, 6-4-09 p5]. Practitioners who utilised chronic conditions self-management frameworks thus formed a particular subset within the participants, a subset who (for whatever reason) had chosen to focus on, and therefore had more exposure to, chronic conditions healthcare as a separate entity. However, despite having a shared language and framework, these participants generally voiced chronic conditions healthcare as a marginalized or misunderstood construct. Elise summarised the differences she perceived between chronic conditions and acute conditions work, in discussing the process of acculturating nurses as they came from hospital positions into a diabetes centre:

> Elise: It's lack of awareness. When people come out with no training... When you've got to sit down and say to people when they come into the centre, 'now let's look at acute and let's look at chronic: what's *different* about them? When a person gets a chronic or an acute, gets a disease, how is their diagnosis made? How quickly are they going to get their diagnosis? Who is going to make the diagnosis? Who is going to treat the condition? Who is the expert in it? Now let's look at the person with the chronic disease', and you unravel all of that. [late career diabetes educator, 18-4-11, p39]

She thus differentiated the diagnosis process: the speed of diagnosis, who makes the diagnosis, who treats the condition, and who was the expert: as completely polarised for chronic conditions as compared to acute. The clarity of her distinctions, alongside specific languages and frameworks I was beginning to pick up on, reinforced my growing perception of the particular styles of engagement and interaction demonstrated by participants– and the distinctive nature of chronic conditions healthcare as patient-centric, rather than disease-centric.

5.3 Defining by describing: using languages from other healthcare sub-disciplines

In this section, I look at other kinds of professional experiences people had had either prior to, or concurrently within, their present positions, and how participants felt these affected their

chronic conditions healthcare style. Participants talked about how they do chronic conditions healthcare largely obliquely, and often through examples from other healthcare sub-disciplines. The following section explores influences from people's career trajectories. It also forms a descriptive analysis, of ways and means which participants found to discuss chronic conditions healthcare, which does not yet have a recognised language across disciplines in the way in which other areas of healthcare (such as midwifery and palliative care) do. Participants used discussion of other healthcare sectors, to form what can be interpreted as a (necessarily tangential) description of chronic conditions healthcare.

To some extent, this is also a strengths analysis. Participants described aspects of former and current practice which appealed to them, and transferable skills which they found useful to chronic conditions healthcare, but which they acknowledged had other disciplinary bases. Skills or approaches participants considered pertinent to chronic conditions healthcare had been learnt from: chronic conditions self-management, community healthcare, primary healthcare, rehabilitation, aged care, palliative care, midwifery, intensive care, aged care, Aboriginal healthcare, social theories, rurality, and/or complementary therapies contexts.

I discuss chronic conditions self-management first in this section, as it is the only professional skill set or influence I came across which included the word 'chronic' in its name. There are also significant DHHS resources being put into encouraging self-management techniques within nursing and allied health community healthcare professionals. The rest of the sub-disciplines discussed are ordered in approximate frequency of discussion within interviews and fieldwork, with the more frequent initially. In a small qualitative sample, lack of frequency of occurrence does not relate to importance: thematic richness and breadth was sought in order to best represent the overall landscape of chronic conditions healthcare as perceived during this research.

5.3.1 Chronic conditions self-management

I use the term chronic conditions self-management in this section to connote an emerging field, which includes formal and informal skills-based approaches as well as more underlying assumptions about the power of patients. Chronic conditions self-management (as a formally named area of competency) is a relatively new skill set within biomedical professions; although attitudinal precepts within it may be considered integral to social work (such as client empowerment, see Healy 2005; Chenoweth & McAuliffe 2008) and some kinds of nursing (for example, rehabilitation Carpenter 2002; Madsen 2013), (mental health nursing Fraser et al. 2002; Crawford, Brown & Majomi 2008). However, formal self-management support training is not yet

a common or obligatory skillset within undergraduate education of most healthcare professionals (it does not appear in tables of content for general medical, nursing or social work undergraduate-level textbooks at the time of writing). While approximately a third of participants were trained in (if not actively using) some form of self-management support, equally a third had not heard of any kind at all. Approximately two-thirds of participants had heard of self-management support approaches, but most were pragmatic about self-management approaches as a limited influence on (or relatively small and sectioned off component of) their work.

Of those who did use self-management support techniques, some acknowledged them as a beacon in their skillset, whilst others saw them as adding to existing practice parameters, rather than as a separate skillset which overrode previous styles of practice. Maree was in the second group:

> Maree: I think it's a, oh I don't know, a philosophical part of my value sets, my personal value sets. And I guess I always struggled in clinical psychology because you always had to be the expert, and I've never thought like that. I've always felt people are their own experts about their own lives. So when self-management came out it sort of really fitted my own philosophies, […] And I think it's because I have a real… one of my really personal values is trying – I'm not saying I'm perfect at it – but that **treating people as equals**. Like, rather than this hierarchical system that I have found myself working in - it's not actually part of my personal beliefs. I think we all have our roles to play and they're all pretty much equal. [late career psychologist, 9-05-12 p5, emphasis added]

She, like Mike, felt that the power-sharing encouraged within self-management paradigms was important. Mike noted that relationships which prioritised self- management shifted the expertise from clinician to patient:

> Mike: I think with some of their stuff, they ["spinal guys"] know… actually probably with a lot of conditions, they know their condition really well. And they know when they're being bull-shitted. So you know, there's no dramas at all if you say 'gee, I don't know, that's a really good question, I'll go and find out'. That's not a drama. Whereas they know enough about their own condition to know when you're having a bit of a stab and you don't actually know the answer. And they've been through it a lot of times, they do a bit of research. And same with some of the muscular dystrophy guys, the MS [multiple sclerosis] guys and all that sort of thing, they know their condition better that we do. And I think **there's a degree of knowing that yourself, as a clinician, you say, 'look, this person's advice is really, you know, as a client, they know their shit'. And listen to them.** Rather than ride roughshod over them cos they might be on a bit of a funny idea. And I think some of the younger guys, and me when I was younger too, you think 'nup, I know more than you'. And, you might not. [mid-career OT, 3-5-10 p6-7, emphasis added]

Self-management training, and the notion of patient as expert, had thus reinforced Mike and Maree's personal understandings of patient expertise and status.

Kate described focusing on preventative health and optimal medication use, as part of how self-management skills were incorporated into her personal style of chronic conditions healthcare. She noted that her own satisfaction was important, as well as client empowerment:

> Kate: I'm concerned with my own personal satisfaction in my job, and how I can help educate people - how they can be in power to actually take charge of their own health, and be a *partner* in their health care. And that's especially important, I guess, with chronic disease, because a lot of people… you know, aren't encouraged necessarily to do that, well, that's not necessarily the right thing to say. But yeah, so empowering them, giving them knowledge so that they can act if they want to. And I really enjoy the role of health coach. [mid-career pharmacist, 5-5-11, p4]

Kate was strongly committed to chronic conditions healthcare as an explicit rather than implicit part of normal rural pharmacy practice; and she discussed taking opportunities as an educator and preceptor to promote that attitude in neophyte pharmacists. She demonstrated the influence of her training in health coaching in actively pursuing opportunities for patient interaction and engagement at almost every dispensing encounter. Isobel was similar:

> Isobel: Every little bit of self-management, *I* believe, is a win. Every little bit that you can possibly draw from your interaction with someone is, you know, they *own* it. And *they* are going to do it. It doesn't matter how minute that might appear on the outside, or whatever you're agreed upon as far as being a way to proceed with something. [mid-career community health nurse/health promotions worker, 6-4-09 p6]

However, self-management support skills cannot at present be assumed to be a common competency in the workforce. For the clinicians featured above, self-management was influential in how they worked with people with chronic conditions: Mike and Maree in augmenting existing frameworks, and Kate and Isobel in extending and providing specific skillsets. Other participants expressed interest in using their self-management training in the future, as different contexts and settings allowed or required, however most were concerned (accurately or otherwise) that such approaches might 'take longer', during heavily booked clinical days.

5.3.2 Community healthcare not hospital based healthcare

A number of participants emphasized that ways of doing community-based healthcare facilitated their approaches to chronic conditions healthcare. Brenda noted that community based work was her love:

> Brenda: I just thought it is such a different picture, because you are actually allowed to practice holistic care, in a primary health setting. You know, in a primary care, you can do the education, the health promotion, the prevention, chronic condition self-management which has only just sort of been around the last few years - but it's much more satisfying. It's a different framework altogether. [mid-career community nurse / DoN, 15-6-09 p2]

More collegial and less hierarchical environments were also considered helpful in facilitating what was perceived as necessarily more autonomous chronic conditions practice:

> Mike: [H]ospital *hierarchy* I think was the thing [I didn't like] – here's the orthopaedic surgeon, here's the orthopaedic registrar, here's the ward DoN, and here's dit dit dit dit da, and we sort of fitted in somewhere in between. And I really *didn't* like that sort of thing. […]
>
> It's *totally* hierarchical. And if they say 'Mrs Gafoops is going home', and I say 'look, she can't get up her steps, and she can't do this and she can't do that and she needs to go to rehab for a week, cos she's a slow progresser', no. If the orthopaedic [surgeon] says she's going home, I can have my vote but it doesn't get me very far. And I wasn't really, it *wasn't* my cup of tea. I just didn't like that sort of stuff. And I mean, theoretically hospitals are getting better, but [indrawn breath]… dunno whether *that* one's in my lifetime. [mid-career OT, 3-5-10 p14-15]

Community based healthcare settings were considered to influence the doing of chronic conditions healthcare, and inherently enable tactics which will be discussed in Chapter 6: 'reinforcing independence' (the healthcare worker as an invited resource rather than an automatic part of institutionalization – in Section 6.8), 'maintaining flexibility' (rather than institutional routines – in Section 6.6), and to 'working beyond the individual' (that is, with patients within their own social and familial contexts – in Section 6.10).

5.3.3 Primary healthcare

Only one participant specifically mentioned primary healthcare as a motivating philosophy behind their style of chronic conditions healthcare; however, a number of others credited it (particularly those interested in self-management) as formative learning within their healthcare careers. Martin had learnt about primary healthcare within a remote Aboriginal work context:

> Martin: … with the influence of CRANA [Council of Remote Area Nurses of Australia], CARPA [Central Australian Rural Practitioners Association], adopting a population health approach rather than a clinical approach. And understanding the difference, the need, well, the simplicity of a primary healthcare approach - community participation, access, promoting access to services, minimising cost, skilling people up for, and then the whole social-determinants-of-health stuff rather than the disease processes. It was all pretty simple really. [late career community health nurse/midwife, 21-9-10 p9]

He had later applied this in rural and remote work in Tasmania, and considered it very relevant to his present rural, regional and metropolitan chronic conditions healthcare:

> Martin: Minimising the adverse lifestyles that are going to cause… you know, so eating well, exercising, keeping your brain active, participating, you know, building social capital, and all the benefits that flow from that – you know, keeping community bonded, I guess, in some way, just a little way, contributing to that. [late career community health nurse/midwife, 21-9-10 p20]

Martin was working as a paid volunteer coordinator as well as in nursing, and considered his volunteer coordination role to be almost more effective healthcare work than his nursing. Such experiences reinforce the importance of tactics which are further discussed in Chapter Six, such as 'working beyond the individual' (Section 6.10), 'reinforcing what is going well' (Section 6.7), and 'reinforcing independence' (Section 6.8).

5.3.4 Rehabilitation

Rehabilitation was another formative work context. Isobel had originally trained in intellectual disability nursing (rather than generalist nursing training), and found that the quite different attitudes, inculcated in that original preparation, carried through to her present health promotion and community nursing roles:

> Isobel: I worked in rehab, and then I worked, my other ticket is intellectual disabilities. And so I worked from a sort of like 'be your best' kind of context, all the time. [mid-career community health nurse/health promotions worker, 6-4-09 p16]

Brenda had also found rehabilitation an effective training ground for her chronic conditions healthcare, and a good transitional buffer for moving from the acute sector (hospital work) to community based work:

> Brenda: [Y]ou are actually rehabilitating people - they're getting up, getting dressed every day, you are teaching them how to actually cope in their home environments again. And to me that was my stepping stone to actually work in the community. [mid-career community nurse / DoN, 15-6-09 p2]

She discussed how working in the community enabled a different style of chronic conditions healthcare to that chronic conditions healthcare which was undertaken 'in rehabilitation'. Rehabilitation in this sense generally takes place in a hospital environment in Tasmania, although sometimes through transfer to a different facility to that where surgery has occurred (for example, after a hip replacement). Mike pointed out that clients as well as clinicians learned techniques from time in rehabilitation, often as much about managing relationships with healthcare professionals as managing their chronic conditions. For Mike, part of the enjoyment in chronic conditions healthcare was about having a different relationship than what he could have with more acute clients:

> Mike: [T]he personal relationship *is* good. And you kind of have it with ten percent of your clients, type thing. The spinal guys, I have it with most of them – mostly because 'here but for the grace of god go I' type thing – you know, similar age group, done similar stupid type things. […] Ride motorbikes, fall out of gliders, do all that sort of stuff, and you think 'ooooh'… - **they're the kind of people who'd be your mates if, if they weren't already your clients type thing**. And hence that, it's a fairly easy banter, and a fairly easy get on type thing. And they, specially spinal guys, as part of their rehab, get trained to be quite assertive in dealing with health people type stuff. They get told, 'no, you ring them up, tell 'em what's wrong

> with you, get 'em out here'. So **they know their rights in the health system, so that's kind of easy, cos they'll ring you up and say 'Mike, I've got this problem.' And they're fairly straightforward about it**. [mid-career OT, 3-5-10 p6, emphasis added]

Working in rehabilitation contexts, or with clients who had been through rehabilitation, gave clinicians exposure to frameworks and ways of operating in less acute environments, with patients who had (to some extent) been trained to be more assertive. It appeared that to some extent, participants were 'being trained' by their patients – that where patients were assertive, participants functioned as a resource and add-on to the patient's menu of options, more than as 'the one provider of solutions'.

Equally, where patients were passive, participants were observed and described working within that more passive frame of reference: responding in ways intended to build confidence, and in some cases to draw out more active ways of conceptualising and acting on their health concerns (see Section 6.3, 'partnering with the patient').

5.3.5 Aged care

Aged care work had been a source of inspiration for chronic conditions healthcare for a number of participants. 'Working holistically', 'reinforcing independence', 'highlighting what is going well', 'working one step at a time' and 'taking the time' are discussed in Chapter Six, and were particularly important to those influenced by aged care practice. Such attributes are promoted as part of a call to 'slow medicine' which focuses on medical and social care of elders (McCullough 2008). However, participants described such elements as crucial to chronic conditions healthcare. Sandra compared the holistic nature of care in aged care and intensive care, to how she wanted to manage chronic conditions (see 'working systematically', Chapter Six). Wendy also mentioned continuity of care as an aspect important to chronic conditions healthcare, whether in the community or in an aged care facility. She had done a day a week at a local aged care facility for ten years or so, and enjoyed the continuity of care she could provide:

> Wendy: I work at [facility name], an aged care residential facility with primarily high care patients. And I come across lots of people there I have been closely connected with through work and outside of work. […]
>
> And often I'm in a better position to see them, because I often treated them out in the community for the last twenty years, so I am in a very good position to know their history. A whole lot of things. Like, I've had a patient who I have seen on and off for 20 years a lot, and she is now in the dementia unit. So I can often provide a whole lot of information that no-one else can, because I know her quite well. So often I am the best person to treat her anyway. [mid-career private physio, 24-5-11 p1]

Continuity of care was not discussed extensively, with participants generally making the best of either continuity (particularly within more ruralised and highly stable population areas within the research), or lack of continuity (discussing advantages of being part-time or a locum, and how that affects chronic conditions healthcare).

Nikki had worked in a nursing home for more than a decade prior to nursing in general practice, but was finding that her personal experience of her own parents ageing was having as much impact as her professional experience on how she approached chronic conditions healthcare. Martin and Isobel also relayed personal experiences of aging parents, and these are discussed in 'reinforcing independence' in Chapter Six (6.8).

5.3.6 Palliative care

Participants who were experienced in palliative care offered interesting insights into their perceptions of chronic conditions healthcare. An initially expressed concern was that not enough chronic conditions patients were being referred to palliative care support in general, and those patients who referred were not referred early enough: 'you get much better palliative care support if you've got cancer than if you've got chronic heart failure'. Approaches prioritised within palliative care appeared extremely relevant and congruent with other participant experiences.

One specialist clinician discussed 'the prioritisation of the human being and their concerns', as an approach she teaches students in hospitals to use across patients, irrelevant of their ward location or organ pathology. She described this as typical of palliative care, but as also an approach which…

> Lauren: …really should be a good medicine approach, not just palliative. [T]hey [health professionals] can't get re-energised and learning again, unless, what I've noticed, unless they've been able to connect with these human beings. And really engage with them, in a way - so that they've been able to communicate with them. And absorb the level of suffering or wellbeing that could be possible with this person. And **get out of the old framework, which is 'you should do this in order for me to give you attention'. And 'you've got to co-operate with me in order to do it'.** [late career medical specialist, 12-12-08 p5, emphasis added]

She was concerned that, no matter the type of patient, clinicians should connect directly with each person, and understand *patient* priorities (as opposed to medical or nursing or allied health priorities). She considered this particularly important in chronic conditions, where she felt late stage care could often be substandard. This prioritisation of the patient and their concerns at the centre of care, which is often discussed in conjunction with palliative care, is also typical of midwifery (discussed in the following section). Such approaches correlate with tactics of 'being

with', 'partnering with', and 'working holistically' with individuals, as discussed in Chapter Six (6.2, 6.3, 6.9).

5.3.7 Midwifery

Midwifery was mentioned by a number of participants as an influential part of their career trajectories. Midwifery is unusual within the western healthcare system, in that it has at its core a more health and wellbeing oriented model; rather than illness, disease, or disorders as the primary reason for patient contact. Women attend prenatal care in order to be monitored for any deviation from normal; however discussions often centre on preparation for a 'normal healthy birth' and baby. Access to midwife-only obstetric care in Australia is generally limited to healthy women within 'normal' parameters, and such midwifery care is largely focused on the assumption that birth is a natural process, and that women are well and healthy when they come to clinicians for assistance in that process. 'At risk' pregnant women are generally referred for medical management via obstetricians, although may also have substantial care from midwives during labour and the birth. It is important to note that midwifery and obstetrics therefore function on very different basic assumptions: obstetrics being generally charged with managing abnormal function, and midwifery with managing normal function (Kirkham 2000).

It was therefore interesting for me to observe how midwifery (with its model of wellness) has come to be influential in chronic conditions healthcare (which, despite attempts to the contrary, for example through self-management paradigms, largely operates from deficit and/or disease models). It appeared that this was partly because many of the nurses had done midwifery at some point in their career, and it was therefore a familiar mode of practice to varying extents for different individuals. One participant was working fulltime as a midwife at the conclusion of the research (at interview had been in community nursing), most had done some midwifery training and/or worked as midwives at some stage, and some had minimal contact and no interest. Of the medicos, two mentioned obstetric training and/or practice. No allied health professional mentioned obstetric work. This means that allied health professionals may have had less exposure during training and careers to (midwifery-style) health and wellbeing-based healthcare.

As an advanced (more autonomous) nursing role and traditional part of nursing careers, it was understandable that midwifery had substantial influence on nursing participants personally as well as professionally; and was mentioned during most nursing professional histories. However, it took me some time to understand what it was that participants were trying to communicate to me, about the relevance of midwifery for chronic conditions healthcare. Elise demonstrated it

most clearly, when she listed a range of former occupations which she considered relevant and of most use to her in her present diabetes education work:

> Elise: I've worked in midwifery where you are working with women toward a very positive end, I've worked in child health where it's the same thing, I've worked with youth about getting them through things to the other end, worked in diabetes which is about getting through things to get to being confident self managers. [Elise, late career diabetes educator, 18-4-11, p42]

She thus clearly construed diabetes education, which I had considered the single specifically chronic conditions 'only' role within the research sample, as (at least some aspects) health and wellbeing work. When pressed, she maintained a perspective that, for her, chronic conditions healthcare was health and wellbeing work:

> Anna: You don't differentiate those… child health from chronic conditions healthcare?
>
> Elise: Well, it's all kind of longitudinal… I don't, I *don't* really. Managing diabetes and bringing that young person along is no different to working with adolescents, it's no different to working with that woman, getting that baby home safely and feeding well, and growing and developing well, really is it.
>
> Anna: If you take it as a health and wellbeing model it's no different, if you take it as a chronic conditions model, it is different.
>
> Elise: Which I obviously don't take it as a chronic conditions model. Cos when you put it in that context, I was going to say, it's not *like* these people have had a heart attack or something, and they've got this thing that's in a box, and it's called a chronic condition and we'll just box it up and fix it all up and then it will go. It's actually *not*, it's about a life. It's about *living* with a condition. So it *is* a health and wellbeing, I guess that's the answer. I don't *see* chronic disease management as anything but a health and wellbeing model. [late career diabetes educator, 18-4-11, p42-43]

While Elise may have been an outlier within participants (most of whom may not be considering patients as largely well and self-managing, social workers excepted), it may be that a habit of focusing on strengths rather than deficits is one aspect of midwifery which was carrying over into chronic conditions healthcare. Midwifery models, while not extensively canvassed for this research, appear more inclined to assume good basic function wherever possible ('every woman can birth a child'), where more biomedical maternity care models might assume that any deficit means a need for early intervention. Equivalent approaches to chronic conditions might involve supporting patients to stay self-managing at home as long as possible, whereas more risk-averse options might suggest increased or earlier medical interventions.

Another way in which midwifery influenced later non-midwifery practice was in its primary healthcare focus. For Martin, primary healthcare aspects of midwifery excited him and carried over into his chronic conditions approaches. He discussed how he had gone to another location to work in a midwifery context, where he considered cultural safety frameworks were more highly

developed, and midwifery more advanced; to have the experience of "seeing for yourself how a better primary healthcare system can work" [late career community health nurse/midwife, 21-9-10 p27]. He later used those same frameworks in his community nursing roles (cultural safety frameworks in particular are discussed in Section 5.3.9 on Aboriginal healthcare). Sandra's midwifery impacts appeared more about operating as an independent practitioner than in terms of a wellbeing model:

> Sandra: As I said before, the holistic – I like doing everything for that person and having it all done. I suppose ticked off and organised, I'm a very organised person. And I wanted all the care done, rather than just going and doing a bath [as in community nursing of that era]. Whereas in general practice I like having my own *room* – it's the smallest room and no-one else wanted it. So I'm happy with that, because no-one will fight me for it. I've got my *own* list of patients. I can see my patients and if I can get time, I can look and see what preventative care needs doing - if they haven't had a blood pressure checked in a year, I can do that while you're here - I can check this and I can check that, and *try* and make a difference. And *stop* someone dropping dead, because their blood pressure's sky high and no-one's checked it for two years. So making a difference. [mid-career practice nurse/nurse practitioner, 16-9-09 p16]

It is possible that midwifery training inculcates instinctive responses for working with people who are 'well' rather than ill. In the same way pregnant women may seek a menu of options to deal with an upcoming issue (such as pain management during labour), some people with chronic conditions may attend for healthcare while feeling 'well', with requests for a range of options to deal with an oncoming health issue (for example, a seasonal exacerbation of a chronic condition). Taking a health and wellbeing approach (discussed further in Chapter Six in Sections 6.5 'working systematically', 6.9 'working holistically', 6.10 'working beyond the individual' and 6.7 'highlighting what is going well') may be an approach that is particularly appealing to certain chronic conditions patients, and instinctively pursued in response to such patients by some clinicians.

5.3.8 Intensive care

Intensive care was an unusual influence, cited by one practitioner only, but communicated very convincingly, and included as a reminder that career influences on chronic conditions healthcare may come from unexpected healthcare areas. Sandra described how using a whole of person approach in intensive care and aged care nursing had affected how she wanted to do her general practice work:

> Sandra: I was really sick of general practice being task orientated. So as a nurse you were just asked to do this ECG [electrocardiogram], or to do this blood taking or whatever. And you weren't part of a team and you weren't being utilised as a nurse, and you weren't seen in the patient as a whole person - which I was *used* to doing, in working in hospitals or aged care nursing I was used to having a whole of a patient approach. Especially working in intensive care, you do *everything* for that person.

Anna: That was your background?

Sandra: Yes. And so I really missed the whole… holistic approach and I didn't like the itsy bitsy approach and I found… I like to always make things better, and I get frustrated when I see things being missed, that… they're not hard things, it's just the system hasn't been in place. So what I've been trying to do in general practice in the last probably 3 years, is work with diabetes and set up the recall system; and set up so every patient with diabetes has a *care plan*. Which, that entitles them to 5 nurse visits, so then I can get them back and *see* me every 3 months. And I can check their different indicators and risk factors. [Sandra, mid-career practice nurse/nurse practitioner, 16-9-09 p2]

The holistic approaches in which she had been trained (in intensive care and aged care) motivated her to create more systematic ways of dealing with chronic conditions, appropriate for work outside institutional contexts. Intensive care thus fed into her approaches to 'working systematically' (6.5) and 'working holistically' (6.9), as will be discussed in Chapter Six.

5.3.9 Aboriginal healthcare

A number of participants had worked in remote Aboriginal contexts, and found that experience influential for their present (rural and regional, largely non-ATSI) work. Maureen actually described her way of approaching work as "vaguely Aboriginal", when we talked about particular styles of healthcare. She talked about being lucky to go to people's homes for her work:

Maureen: I like to sit down and talk to people, find out who they are. What's happening in their lives. Rather than come in and say 'you've been referred for this', and away we go.

Anna: Did you say vaguely Aboriginal?

Maureen: Yeah. You know – that feeling of needing to know where people are in their lives and all the rest of it. Which you wouldn't dream of doing in the clinic, because you haven't got time to mess around like that. So… that more… what did one of my students say to me, she said, 'you've got a very conversational style of interviewing someone'. And yeah, I find that a bit easier, just to… chat to someone, and work back to what I want. [late career community physiotherapist, 3-5-10 p6-7]

She explained that this actually simplified work for her in the long run:

Maureen: Because if I take that longer time, the first time I see someone, I've learned a *lot* about that person and what sort of social support or whatever that person might have. So that I can *be* more direct next time I go in. Or I feel comfortable having a conversation with them over the phone about a particular issue. [late career community physiotherapist, 3-5-10 p6-7]

It was clearly important for Maureen to be respectful and to have a broad initial conversation, which could also function as a social history and memory trigger for future consultations, as a way of easing into more threatening issues such as assessing mobility. Taking extra time, and possibly a more indirect but (in some ATSI cultures) more respectful route, were her preferred ways of operating. 'Taking the time' (6.11) and 'partnering with' the individual (6.3), whilst

'reinforcing independence' (6.8) through respectful interaction, are key to both Aboriginal healthcare and chronic conditions healthcare, and discussed in Chapter Six.

Working in ATSI communities had been very inspiring for some of the participants, and that inspiration carried on beyond their tenure in Aboriginal health services. Mike described the creativity and flexibility possible in small communities and Aboriginal health as very motivating:

> Mike: [T]hat's where **I really like the Aboriginal health stuff, you can be *very* lateral, cos nothing works. It justifies almost any action, as long as you don't kill anyone**, cos the last action you know was of course a disaster. But yeah, that ability to say well, here's a problem, let's start from a clean sheet. You acknowledge what hasn't worked before, and off you go, ok, what's our next logical step, let's give it a try. Yeah. And I think **in a smaller community that works even better. So you know, if we're doing stuff [in remote location], you go out with the handy man**, say 'this is a really crappy old house and it's going to fall over, how the hell are we going to fix this one?' […] One of the handy man's great, he re-stumped a little old lady's house for her, 'cos **the floor was all wonky and her wheel chair kept sloping down, he said, 'oh, I can fix that!' And throws himself under the house, re-stumped it and wedged the house flat**! And I think anywhere else, getting the house re-stumped by the handyman…
>
> Anna: Could have been thousands.
>
> Mike: **It would be thousands. Or if the department found him doing it, you know?! But in [remote location], that was fine, everyone knew Trevor did that sort of stuff.** That was him, that was his cup of tea, he was safe and we just don't ask any questions about that sort of thing. And it resolved my issue with the little old lady. […] And you know, the house was worth three hundred bucks, so you couldn't, and the person had two hundred in their bank account, so **it was never going to get fixed any other way. So *that* sort of flexibility I really like about small systems. And that ability to work as a team, where you actually, you know, you accept everyone's limitations, and you all fill in holes for each other – it's a two way street.** I do quite like it. [mid-career OT, 3-5-10 p36-37, bold emphasis added]

Mike thus noted that 'maintaining flexibility' in terms of service utilisation and opportunistic quick solutions were crucial to chronic conditions healthcare, as well as in Aboriginal healthcare.

5.3.10 Social care theories

Whilst only one participant (social worker Billie), specifically credited social care theories (healthcare theories located in social rather than individualistic domains) as influential on their chronic conditions practice, many participants had experienced social theories within healthcare. Participants specifically described aspects of social determinants of health, primary health care, health promotion, public health, and population health as influential on their chronic conditions healthcare. While most had not had direct experience of these more socially informed sectors of

health care, those that did were clear about the formative influence these had had (see also Sections 5.3.3 Primary healthcare, and 5.3.9 Aboriginal healthcare).

Only one social worker was observed and interviewed for this research; however social work literature was also reviewed. Social work, alongside nursing, is one of the more theorised of the healthcare professions, and the most specifically theorised socially (theories about social rather than individual determinants for care pathways and models). Billie thus provided a somewhat different window into chronic conditions healthcare within this research. As normal for a state funded community social worker, Billie's position description incorporated case work, group work, community development and health promotion; and she described her manager as firmly resisting any attempts to shift the balance away from equal time allocations to each of these components (against some pressures to move towards client-focused case work only). She also had a slightly different chronic conditions clientele to other participants: "things like longterm mental health issues, alcohol and drug issues, rather than perhaps clients that have got diabetes and osteoporosis [without coexisting social issues]" [Billie, mid-career social worker, 22-06-09 p1]. She emphasized that, in her experience, most of the people she dealt with were not sick, and did not have a chronic health condition. She also considered a standard social work model to incorporate self-management expectations:

> Billie: That people will be able to do it themselves, yes, or give people the skills and they will be able to manage their own health. […] And most social workers see all the work that they do as being very client focussed, and very client… empowering. [mid-career social worker, 22-06-09 p21]

She perceived other less theoretically informed professions (such as medicine), and less trained case workers whose roles crossed into social work (such as rural financial counsellors), as rather less equipped to understand the social dimensions of chronic conditions:

> Billie: They don't have an understanding of social dynamics, social theory - you know, class and justice issues, which we do when we train to be social workers. […] It fails them because they… tend to treat people as individuals without treating them in a social context. Or treating issues as individually based, rather than society based. And if you think that issues that a client presents with are really just to do with that client, it affects the way you advocate for that person - or it affects the way you think of addressing issues. [mid-career social worker, 22-06-09 p6]

Whilst it would be premature to draw any conclusions based on a single participant from social work, the literature indicates that social work is clearly a profession which looks to 'work beyond the individual' (Section 6.10) and 'reinforce independence' (Section 6.8). Given that participants other than Billie also clearly cited socially informed approaches (such as primary healthcare and

health promotion), social theories need to be acknowledged as formative within participant understandings of chronic conditions healthcare.

5.3.11 Rurality

The rural pathway of one participant had determined not only her present role, but also her style of operating within that role. Other participants also described how their rural locations influenced their practice as a whole, and while most of their observations are already well corroborated in rural health literature, similar issues (such as personal-professional boundary management, the need to be a specialist generalist, the value in local knowledge and networks, work-life balance, and the creativity and flexibility inherent in smaller communities) were considered relevant to chronic conditions healthcare.

Joanne was a rural health promotions officer, and the only research participant whose role did *not* include formal one-on-one healthcare provision. She had gotten into health promotion "by accident":

> Joanne: I fell into it, but I think that's the beauty of working in rural towns, is that because they can't get, they can't attract people who have degrees that live in the cities; it's a matter of training up the people that live there already. [health promotions worker, 2-7-09, p8]

She emphasised that it was the rural experience that she had, which had made it easy for her to engage with a similar rural community to the one she lived in:

> Joanne: You know, we already understand the community, so we can actually work easier in the community. [health promotions worker, 2-7-09, p7]

She discussed the importance of health promotion within rural communities, and emphasised that in her work it was important not to 'make people identify as being sick', although she estimated that fifty percent of people who turned up to events had chronic conditions. She described an approach to working with these people as one I would characterise as 'flying under the radar': by indirect and whole-of-population rather than specifically targeted approaches. She said that she might well choose to have health-promoting discussions with individuals during public events, however that her job description and professional expectations specified only group work.

Joanne noted that fundraisers for particular causes had the best turnouts, rather than solely information provision without charitable intentions for the same condition (such as, cancer morning teas). She considered this part of a rural culture of 'helping out' and noted that

fundraising events were great tactical opportunities for her work. She also described using different tactics for different genders:

> Joanne: To attract men to something, you don't want to put 'health', or 'mental health', or anything like that on there.
>
> Anna: Sickness. Prostate.
>
> Joanne: [laughing] Nothing. Because that just scares them off. And the way, like the [location] Men's Shed that I was involved with, we've actually got a mental health worker there who's a male, who goes along to the Men's Shed every week. […] And if the guys are talking about their health he'll give them some information and that, but he doesn't go in there and say 'OK, drop your tools, I want to talk to you about health'. […] **Because in smaller communities you've got to build up that trust first, before you can actually say 'I think you should change your lifestyle'.** There's got to be trust there with the members, to actually… be up front with them like that. [health promotions officer, 2-7-09 p8-9, emphasis added]

She emphasized it was the building of trust, which made referrals to one-on-one services possible, particularly with people who were otherwise unlikely to seek help. Equally, people who had been referred to health promotion activities (such as a walking group) were unlikely to want to identify as being there because they were 'unwell'. If people wanted to bring up concerns (illness, personal, or social) during such events there was an openness to it, but not a focus on illness *per se*. It was thus important that whilst also providing for ill health, the health system incorporated working with people to maintain wellbeing.

Joanne's experience, of doing chronic conditions healthcare by stealth or indirectly, supports the tactic of 'working beyond the individual', which is discussed in Chapter Six (Section 6.10). In another sense, a rural resident being trained for a position within their community also represents 'working beyond the individual': in that by training people within communities to become health workers in their existing locations, recruitment and retention issues may be lessened.

5.3.12 Complementary therapies

A final observation draws attention to an area of chronic conditions healthcare which this research made no attempt to explore: the role of complementary therapists in chronic conditions healthcare. However, one GP I observed had plaques on her wall indicating completion of training in complementary medicines. During the afternoon in which I observed her, I didn't notice anything I would categorise as 'alternative'. However during our interview, she described her use of complementary approaches (including dietary approaches) as necessary to working holistically:

> Caitlin: Like, there's often a lot of things that are not appropriate really to use heavy duty pharmaceuticals for.

Anna: For example?

Caitlin: Like indigestion. There are a lot of simple remedies for that without prescribing proton pump inhibitors, which people do willy nilly, and the same for weight loss, it's a big area. Same for all the diabetics, looking at actually their diet and other chronic diseases you know - hypertension and ischaemic heart disease - you've *got* to look at the whole picture, haven't you. So I think it's always *part* of what you are doing in a smaller, or lesser or greater way; once you get interested in it. [late career GP, 10-12-08 p4-5]

She described training in bodywork after having problems with her back, and then doing further study subsequent to the bodywork modality; however, did not consider her complementary or alternative training to be at the forefront of her medical practice. For Caitlin, training in complementary medicines was more a way of reinforcing 'working holistically' (see Section 6.9), and 'working one step at a time' (see Section 6.4), than an alternative to conventional medical care per se.

5.4 Towards a Working Definition of 'Chronic Conditions Healthcare'

Chronic conditions healthcare can therefore be summarized as healthcare work in which advice and support relates to one or more long-term conditions. It includes 'once off' and more regular instances of chronic conditions generated work ('work occasions' or 'patient encounters'), clinical work, administrative work, inter-professional work and interpersonal work. It crosses the spectrum from health promotion, through monitoring and maintenance work (community and residential institutional), into acute management work (community and hospital), emergency treatment, and palliative care work. Particular disciplines of health professionals may be more commonly allocated or expected to perform certain chronic conditions related tasks (for example, diagnosis, medication dispensing), while other tasks may cross-disciplinary boundaries (such as, care planning, symptomatic relief/management, case management, disease/symptom prevention).

As an example, it may appear that someone breaking his or her arm is a clear case of an acute condition. However, a chronic condition may impinge on the capacity of a fracture to heal. For example, diabetes generally leads to poorer vascular capacity, and therefore poorer wound and break healing; equally, heavily medicated asthma may require longterm steroidal medications which may induce osteoporotic changes. In such cases, even the simplest of fractures may require more complex support than 'normal', and thus become 'chronic conditions healthcare'. In an aging population with increasing chronic conditions incidence, more fractures may be experienced by people with chronic conditions than by people without them. It may thus become more 'normal' to treat fractures as if for a person with a chronic condition, than to treat a person

without a chronic condition for a fracture. A focus on chronic conditions healthcare, including work towards a clearer definition, can thus assist clinicians and healthcare systems as they adapt to a new 'normal'.

The working definition provided above is thus explored further in Table *.*, and provides as a hypothesis for testing in different contexts, within the rest of the thesis and beyond it. As Mol suggests, entries on this list "are not necessarily coherent"– they may not be exhaustive or exclusive, and clearly have "linkages but also tensions" between them (Mol 2012) p126. Some aspects may be exclusive to particular professions; however most are undertaken by more than one profession. Many participants in this research would argue that chronic conditions healthcare also involves ongoing relationships between practitioners and patients, however a comprehensive definition needs to take into account episodic work as well as ongoing. As with any definition, it needs to be tested and extended by the stakeholders to whom it is relevant, and adjusted situationally.

Chronic conditions healthcare is therefore:

1) Work with particular individuals *with one or more chronic conditions*, on a once-off or regular basis:

Clinical work

- screening, investigations, and initial diagnosis
- on going monitoring / screening tests related to an existing chronic condition
- formal/informal counselling about a condition (for example, motivational interviewing, assisting behaviour change such as weight loss, giving up smoking, general encouragement to stay on preventatively aimed drugs)
- re-scripting for regular drugs (for example, asthma preventatives and acute treatment drugs, antidepressants)
- managing drug interactions and side-effects (particularly where multiple chronic conditions co-exist, as is often the case in older patients – for example, antihypertensive + anti-cholesterol + anti-asthmatics + antidepressant)
- regular debriefing about broader life impacts of / solutions for chronic conditions
- managing exacerbations (for example, more frequent asthma over winter)
- managing acute presentations (having an asthma attack right now, but not 'emergency')
- managing emergency presentations of chronic condition (having a serious asthma attack right now)

Interpersonal work

(that is, between health professional and patient – potentially alongside other roles in smaller contained communities, such as both volunteering in a mutual interest group)

- keeping the relationship/s going, professionally and/or socially – for example, encouraging someone to keep attending healthcare provision where helpful to maintaining good health &/ chronic conditions status maintenance (especially where no script is required)
- ending the relationship – 'breaking dependency'
- maintaining boundaries between personal and professional roles

Paperwork / administration

- writing complex care plans
- writing case notes
- writing referral letters / written reports or updates on patient status
- regular updating of care plans to current Medicare specifications

Inter-professional work

- writing referral letters / written reports or updates on patient status
- confirmation of case plans
- talking with GPs and specialists, including allied health, pharmacy, nurse specialists, community nurses, practice nurses (in person or by phone) – casual or case conferencing
- planning shared education work

2) Work with individuals *without chronic conditions* which is generated by the prevention of possible chronic conditions:

- screening family members of those with chronic conditions
- general population screening for risk factors / where risk factors exist, for disease/condition

[Note: both of these may generate some or all of the above mentioned clinical, interpersonal, administrative and inter-professional work]

3) Work with groups which is chronic conditions-related:

- health promotion activities (for example, high-school health programs)
- group education (for example, cardiac rehabilitation, chronic conditions self-management course)
- support groups (for example, walking group, condition-specific group)

5.5 Summary

Despite acknowledging chronic conditions healthcare as a substantial portion of their daily activity, participants initially found it difficult to conceptualise chronic conditions healthcare. When pressed, they defined it largely in terms of diseases and conditions, and associated practices. This means that chronic conditions healthcare remains to a large degree implicit and to some extent invisible, or at the very least not much considered or reflected upon. This concurs with gaps in existing literature (as identified in Chapter Three). The findings presented in this chapter suggest that, for participants as well as for patients, chronic conditions healthcare is experienced as fragmented.

The first part of this chapter presented ways in which participants define chronic conditions healthcare, often obliquely: through quantifying ('how much of this work I do'), through examples of practice ('this is the kind of work I consider to be chronic conditions healthcare'), and through comparisons and contrasts ('this is the kind of work I don't consider chronic conditions healthcare'). In the second half of this chapter, participants described a dozen formative influences which, alongside situational contexts, coalesced to create their present approaches to chronic condition work. Transferrable skills which participants utilise from these sectors are discussed in more detail in Chapter Six. Implications of the general invisibility of chronic conditions work will be considered in Chapter Nine.

None of the participants described an early vocation or intentionally directed career path where they aimed solely to do chronic conditions healthcare, and most simply accepted it as (a substantial) part of their broader healthcare remit. Participants nevertheless identified previous work experiences which strongly influence how they *approach* working with people with chronic conditions, as well as how they *talk* about doing chronic conditions healthcare. I suggest that participants are in the process of creating their own shared languages, (largely individual) chronic conditions healthcare rhetorics, which they may utilise with patients and immediate co-workers (for example, GPs with practice nurses and vice versa, allied health workers within shared office zones, within community nursing teams, and so on). Career trajectories and colleagues, as well as the presenting patients, thus influence both how participants define, and how participants actually do chronic conditions healthcare.

In Chapter Five, I commenced a process of conceptualising chronic conditions healthcare. Chapter Six deepens this, as I examine in more detail some approaches and practices which participants bring, and consider integral, to chronic conditions healthcare.

6 'Finding and Sustaining the Hook': Doing Chronic Conditions Healthcare

6.1 Introduction

Chapter Five examined 'what' chronic conditions healthcare is, providing a foundation for this chapter where I examine 'how' chronic conditions healthcare is done. In Chapter Six, I am responding to Research SubQuestions 2 and 3:

> RSQ2: what are the strengths of chronic conditions healthcare professionals?
>
> RSQ3: what are the strengths of chronic conditions healthcare itself?

As throughout Part Two (Chapters Five to Seven), 'how people do chronic conditions healthcare' was identified from observations, semi-structured interviewing (involving direct and open-ended questions), and from video-triggered interviews. Other sections outline what chronic conditions healthcare might be (Chapter 5), and under what conditions this kind of work is possible (Chapter 7). However it is in this chapter that I explain how I *observed* participants approach, and how participants suggested that they *do* chronic conditions healthcare. These observed and suggested foci form fundamental chronic conditions healthcare principles.

I demonstrate that chronic conditions healthcare is qualitatively and pragmatically different to other kinds of healthcare work; by naming up participant principles, skills and approaches, which they considered relevant to chronic conditions healthcare. While these attributes are not necessarily unique to chronic conditions healthcare, the preponderance of them across a diverse range of clinicians and clinical contexts specifically asked about chronic conditions healthcare, suggests that there are characteristic aspects which signal the presence of chronic conditions healthcare. In providing examples of how healthcare professionals do chronic conditions healthcare, this chapter deepens understanding of the nature of chronic conditions healthcare.

It was sometimes difficult, for both practitioners and myself as a researcher, to understand what it was that we were trying to describe, given that chronic conditions healthcare is ubiquitous and intertwined within other more formally labelled professional disciplines (primary healthcare, primary care, general practice, community nursing, palliative care, Aboriginal healthcare and so on). I argue that it is exactly this ubiquitous and entwined nature of chronic conditions

healthcare, alongside the rising incidence of long-term conditions themselves, which necessitates focused attention. Participants made it clear that chronic conditions healthcare involves a range of activities, techniques and tactics, which skilful providers synthesize into individual treatment styles (personal inclinations towards particular ways of professional functioning) and modify as necessary for different clients or clientele groups. In this way, participants are "appropriating, resisting, and hybridising" (Dombroski 2012, p. v) existing professional care-giving practices, in order to create their own personal syntheses, 'versions' of chronic conditions healthcare.

In this chapter I excise individual aspects from what normally presents as amalgams, in order to examine the commonalities in what it is that health professionals doing chronic conditions healthcare do, and how it is they do it. Chapter Six outlines some 'trajectories, tactics and rhetorics' (de Certeau 1984, p. viii), which I observed and which research participants describe as important in delivering care to people with chronic conditions. They are presented as equally important potential approaches, and may operate simultaneously or sequentially. While every participant could be represented in at least one of the approaches, and most in more than one, they are not presented in order of frequency or priority, but should be considered as a kind of implicit menu of options, which clinicians utilize.

6.2 'Being with' the individual

The most striking demonstration of a shift in emphasis within chronic conditions healthcare is found in the descriptions participants gave of patient-centred care, often described as 'being with' the individual. Most of the twenty-six participants spoke about the importance of focusing on the individual in front of you; *rather* than condition-specific checklists, differential diagnoses, potential treatments or solutions. They considered this fundamental to all healthcare work, but imperative in chronic conditions healthcare in particular; and used quite particular imagery, which differentiated this approach from others discussed in this chapter. For example:

> Elise: It really is about being with that other individual. It is not 'here I am and there you are and I'm the expert and you're the person *with* a chronic condition', or 'here, you've brought your diabetes along with you'. It's 'how can *I* help *you* - live with your condition in a way that you want to live'. [late career diabetes educator, 18-4-11, p25]

'Being with' may be derived from mindfulness or meditation-based therapies (eg Mindfulness-integrated Cognitive Behavioural Therapy [MiCBT], (Cayoun 2011), or align with 'person-centred' or 'patient-centred care' (see Bauman, Fardy & Harris 2003; Pulvirenti, McMillan & Lawn 2012), and was, for some participants, an over-riding ethos. While no participant

specifically listed mindfulness as an influence, about a third of participants used the phrase 'being with'. One participant described herself as Buddhist, and another had extensive personal and professional experience of meditation practices [Lauren 12-12-08 p32]. Interestingly, the participant above considered herself a non-practising Christian, but also discussed seeing herself "as a part of something beyond yourself […], always belonging to a bigger organism" [Elise, late career diabetes educator, 18-4-11, p36].

Lauren discussed the shift she had made intellectually and emotionally as a clinician, from prioritising her own needs as a health professional, towards making the patient 'the centre of the universe':

> Lauren: I moved away, I saw the error of my… this belief that 'they're my patients' was a real, not an epiphany for me, but a sense of 'what the hell am I doing? Whose needs am I meeting here?' And they were mine. My need to be a competent professional, a specialist, or… It really started me questioning. So I started really focusing more on all the things that I'd learnt in palliative care, but perhaps hadn't integrated. Which was, 'who is the centre of the universe here?' Well, it's the patient at this point in time. For this moment, it is the patient. Yes, I have my universe, and everyone else, we have to inter-react, but I'm not blind now, it's not just my centre of the universe. [late career palliative care specialist, 12-12-08 p14]

Brenda and Elise were similarly inclined, and described their plan of attack as starting "from wherever the person is" [Elise, late career diabetes educator, 18-4-11, p29]. Brenda credited her use of this approach to self-management support training; however, Elise stated that she didn't use any particular branded method of chronic conditions healthcare, but prioritised intense focus:

> Elise: So it's actually just being very very real, and very in the moment, and very *with* the person. [late career diabetes educator, 18-4-11, p29]

Others talked about the importance of getting to know what a patient wanted out of this particular consultation. They felt it vital to get to the nub of the current problem as the patient perceived it:

> Caitlin: I suppose, to me, I more concentrate on getting to know the person as an individual, and then deciding which particular approach or whatever would suit them, *as they are*, rather than setting out to change them as such. [late career GP, 10-12-08 p6-7]

Elise considered this particularly important in the opening moments of a consultation:

> Elise: So really, for me, it was to say 'why do you think you're here?'. Because, regardless of why people are sent, they've come for a reason, they don't have to come. […] It is *completely* voluntary. 'So what got you through the door today?' […] What's *driving* this person to come and sit in a room with me, as a diabetes educator? Because people come with *something*, a sense of wanting something. [late career diabetes educator, 18-4-11, p26]

It is clear that participants wanted to know where their patients were at *before* proposing any therapeutic or diagnostic intervnetions.

Participants considered care and management that considered the broader individual context and immediate experience vital, not only because different chronic conditions require different interventions, but also because they had experienced different people with the same chronic condition responding differently to treatment. Whilst this is also the case in acute conditions, it is possible that with the extended timeframe of chronic conditions, there is more time for biological, cultural and personal idiosyncrasies to impact on treatment and therefore more need to take such into account. Participants described being aware of individual requirements, as demonstrated by Kate, who highlighted the need to distinguish between people newly diagnosed and those who had had chronic conditions for a long time:

> Kate: I think it's just recognising the different needs of the person, and the different emotional status of the person. Someone with a chronic condition, or recently diagnosed with any sort of short term acute condition, has a degree of shock - whereas when you are working with someone who has been *living* with a chronic condition, it's more a fatigue. […]. Yeah, I think everyone is so different, it's really about the individual and their capacity to take on what you're telling them. [mid-career pharmacist, 5-5-11, p8]

For Kate, focusing on the individual was about knowing the patient's stage of disease trajectory or level of familiarity with their conditions, as well as 'being in the moment' of the consultation. Caitlin emphasized:

> Caitlin: So when you say 'how do I keep interested in giving the same advice': each patient is *really different*. And they're all so different from a psychological point of view. So there's the two aspects really, there's the physical and there's the psychological if you like, so you're always having to mould your advice or your approach according to the person's psyche as well, so determining that is part of the process. [late career GP, 10-12-08 p6-7]

She suggested that the moulding of advice and approaches to individual physical and psychological needs was crucial to sustaining interest in doing longitudinal work which might be perceived as repetitive or unsatisfying: "I guess if you take up the interest in people as individuals, then it's *never* the same." [late career GP, 10-12-08 p6-7]. Another GP agreed:

> Heather: I keep on going back, and I've mentioned this to you before, […] about reading that article on 'each patient is fascinating'. And each patient *is* endlessly interesting. And that when you see, when you try and get *some* inkling of their life, then *that's* what makes them interesting. And you're not just doing the same old spiel over and over again […]. But when you're doing it, when you know their daughter's getting married, or they've just had a grandchild, or their mother died last week - you know, all those other things that go on, then they're a patient in *context*, and they're not just a diabetic. [mid-career GP, VTIii 16-12-08 p10]

These clinicians noted that the contexts of their patients created inherent complexity and interest, which influenced their chronic conditions healthcare responses to both diseases and treatments. In some ways, it was the differing contexts as much as the differing patients, which required customisation within each relationship, and enabled intense engagement. Inherent interest in a patient motivated personal engagement with that patient, and therefore more detailed or tailored chronic conditions support.

Some participants had developed an awareness of the importance of one-to-one support irrespective of particular clinical roles. Tracy discussed an inability to use generic health coaching skills in her present caseload where many patients needed specialist advice, but noted that it was really important for her to check in with people as individuals:

> Tracy: And [the mother of a disabled child] said, 'you know, that dietician is the only health professional who's actually asked *me* how I'm going'. […] So like, if I've seen someone for a follow-up appointment, I do say to them, '*how* are you going?'. '*How* are you coping with that?', and it's not just nutrition counselling, but you feel like you're counselling them in their other, sort of non-nutrition life, as well. [early career dietician, 6-5-10 p16]

These clinicians noted that it was important to really connect with each individual in a consultation, and that the actual connection (as well as improved information gained through such connection) influenced their professional responses (choice of treatments and styles of delivery). In the same way that 'being with women' is considered central to midwifery (see Kirkham 2000), 'being with people with chronic conditions' may be central to doing chronic conditions healthcare.

6.3 Partnering with the patient

Partnering with the patient was a recurring theme in most of the interviews. For primary healthcare, chronic conditions healthcare is often about both *rehabilitation* (from active disease status or acute event) and *maintenance;* of lifestyle changes, self and/or external monitoring regimes (of biological markers such as blood sugars or warfarin levels), and treatment pathways. Both rehabilitation and maintenance require partnering with patients, ideally with patient ownership, in order to commence and continue "a forever project" (Madsen 2013, p. 180). It appeared that, for chronic conditions, unlike in working with people with acute conditions, research participants generally felt a need for the patient to be more engaged, and preferably, as Sandra states below, "in the driver's seat". In acute situations, health professionals are used to taking charge and controlling the scene. However, in chronic conditions healthcare (other than

acute exacerbations), participants within this research demonstrated clear attempts to devolve control to the patient. Sandra emphasized this during her video-triggered interview:

> [Consultation video transcript - clinician talking to patient]
>
> Sandra: … and we'll have all the dates when things are due, and that'll be your copy and that puts you in the driver's seat too, because then you can go 'ooh, it's November, I need to see Sandra for more blood tests'.
>
> [Audio of subsequent interview transcript - clinician talking to researcher]
>
> Sandra: What I am doing there, um, I'm leading her in the path of being more engaged in her care. I'm saying, you know, "I am giving you this care plan, which we have done together, in collaboration. We've discussed it. And on the care plan there'll be a date there, December. And I'm really happy if you call me in December and say 'look Sandra, I'm due for my blood tests'" - giving her permission to take ownership. [video replay restarted]
>
> [Consultation video - clinician talking to patient]
>
> Sandra: … we want you to be a big part of the team - you are the centre of the team. [mid-career practice nurse/nurse practitioner, VTI 21-9-10 p9]

Similarly, Josephine described her work with an oncology patient:

> Josephine: [W]e had a gentleman I've been involved with for quite a few years. And the first time he came along he came along with a folder like that, opened it up and was writing notes, and I thought, oh, okay, right. And yeah, built up a very good relationship over time, over years. And I had a card from him, and he was the captain of the ship and he put me down as the first mate, something like that, this relationship we had with managing his disease. [late career hospital medical day unit, Director of Nursing (DoN), 25-9-08 p5]

'Driver's seat' and 'captain of the ship' metaphors emphasize the importance of partnering with patients even to the extent where the patient feels that they are the driver, the expert, more than the clinician.

Research participants observed that capacity for partnership differed with various patients (as indicated in chronic conditions self-management literature, eg Bell & Orpin 2006; Greenhalgh 2009). All participants considered that there were certain types of clients that could be partnered with or coached, and others who needed more directive advice and even simply expert information. Generational variances were particularly clear:

> Sandra: Because in this age group, they are less likely to take ownership, and expect the doctor and the nurses to *care* for them, than if they are younger.
>
> Anna: How old is she?
>
> Sandra: She's 49. So like, if they're in their twenties, they're a bit more proactive and they're on the internet checking this, checking that, they know more stuff. Whereas in this age group, we're trying to engage them more in taking ownership of themselves - so

> giving them the care plan and saying 'this is *yours*, *you* ring me'. And 'if I haven't heard from you then, I will ring you', but try and lead them into initiate their care. And to *know* when their cholesterol is due, to know when their next blood sugars is due, for *them* to know. [mid-career practice nurse/nurse practitioner, VTI 21-9-10 p9-10]

This patient worked in retail and was not tertiary-educated: self-management literature describes difficulties for lower socioeconomic and blue-collar workers, as well as the pre-war generation (those born pre WWII), in taking active rather than passive patient roles (Taylor & Bury 2007). Sandra was aware this kind of patient would have extra barriers to taking a more active role, but was prepared to put extra work into building self-confidence and self-efficacy that could make a more substantive difference to the patient's overall health longterm.

Readiness for partnership could also be condition dependent. Tracy considered certain conditions as unlikely to be able to be coached:

> Tracy: [I]t depends on whether they're lifestyle or not. So, for example, cerebral palsy – I don't know if you consider that a chronic condition or not, but they need management from their peg feeds, saliva management through speech pathology, they need bowel management as well – they often have all sorts of problems. So with those, they actually do need… I don't feel that you can *coach* them – the carers. You can coach them to a certain degree, and it depends on their level of understanding as well. [early career dietician, 6-5-10 p12]

While cerebral palsy was a long-term condition, the interventionist nature of supportive treatment for severe cases meant that patients and carers for patients were more likely to be seeking clinical support for treatment specifics and management of treatment sequelae.

Equally, where surgery had created a sudden change in functionality, a more directive role was necessary. One patient had had major oesophageal surgery but was unclear why she was on a pureed diet:

> Tracy: I basically went through with her, the whole anatomy of what her procedure was, what had been done, and the thoughts on why she had to eat as she did at the moment. Um, but that's sort of like, an expert opinion, a specialised thing. I mean, you don't go to a surgeon to be coached on 'ok, what do you think we need to do to make, what sort of surgery do you think we need to do?' You can't do that, with a lot of these cases – they do actually come to you for advice. [early career dietician, 6-5-10 p13]

Participants emphasized the need to partner with patients, but as appropriate to the context of responding to the person in front of you: individualizing the treatment and management style to each person and their particular needs.

About one third of participants considered self-management support training had influenced their level of partnership within practice to varying degrees; from incorporating the use of particular questions regularly (for example, 'how do *you* think you'll fix/approach this?'), through to refusing to take work which did not enable self-management approaches. Brenda believed her practice style had changed substantially, and that doing chronic conditions self-management training had transferred into situations where she was not formally employed to do self-management support:

> Brenda: I found that my way of actually interacting with people transferred across to my *other* clients, in the community. So I was actually listening more, to *them* - not trying to solve their problems but asking them what they wanted to do. Because, traditionally, community nursing has been about problem solving – they'll say 'I'm worried about this, that and the other'; and I would say 'well, you can do this, you can do that', you know: 'these are your options'. Whereas now, if somebody said they were worried, I would probably say 'well, have you thought about how you could go about fixing this?' - how could *you* do it, what could *you* do. And **just ask leading questions. So it's a different approach, to how you actually approach people. Making it, putting it back on them - not providing the answers.**
>
> Anna: So that has been the really big shift for you in twenty-three years?
>
> Brenda: Oh, *incredibly*. Because, being a community nurse, I'm always telling people what to do. But I tend not to do that anymore. You know, I *advise* them, and I give them the information to make their *own* decisions, or I try and source out what *they* want to do about things. […] So that has been an enormous shift. [mid-career community nurse / DoN, 15-6-09 p21, bold emphasis added]

Most participants acknowledged that they had felt that they were already good at partnering with patients prior to self-management support training, and indeed, to some extent had thought they already enabled self-management as much as was possible within the healthcare context. However others credited self-management support training with attitudinal shifts in how they approached their patients, and felt they had improved their self-management enabling subsequent to training.

Some participants identified it was important to take on the roles of partnership and patient engagement with *carers*, as much as with patients. They considered that carers their patients as much as the actual patient, and that it was a normal part of good healthcare to support those near to a patient as well as the patients themselves. An example of this was when nurse Isobel was observed encouraging 70-80 year old Mary to write a list of questions and then ring the hospital herself for information about her husband, rather than have Isobel ring for her. He had been hospitalized for the second time after falls, and the community nurse 'dropped in' during her rounds to see how Mary was going. In the subsequent interview, Isobel described the process of gently encouraging Mary to do more for herself in managing her own health as well as her

husband's, referring to this as needing to operate within a 'cultural safety framework' for that age group:

> Isobel: [W]ith Mary, it's culture around 'you fix it' and me saying, 'we can work together' and 'you *can do this'* - so that's as much as Mary will take, within her cultural context. [community health nurse/health promotions worker, 6-4-09 p18]

Isobel found the process of establishing an attitude of self-management particularly rewarding:

> Isobel: Something really special happens when they get it, when they realise that I'm not going to tell them what to do. Like with Mary, we're a long way off with Mary. She would still like me to tell her what to do. And in a lot of ways, today was still edging forward, to say, 'are you confident you can do this?'.
>
> But it's good, good that she's at this point, you know, that 'I'll do this'. This lady, previously she would have nurses doing all of that. 'You're the nurse, you do it'. […] [laughs] Like, people on the island, aren't all going to embrace this. It's going be something that, we've all got to be really clear, that for some people it's a hard sell. [community health nurse/health promotions worker, 6-4-09 p5-6]

For Isobel, encouraging self-management attitudes in carers was as important as encouraging self-management in actual patients.

Some researchers argue that people with chronic conditions are almost inevitably considered 'difficult' (see Lubkin & Larsen 2006, p. 12). Caitlin discussed some chronic conditions patients as 'heart-sink' patients, but felt that:

> Caitlin: Heart-sink is a bit of stupid word. Heart-sink means you haven't learnt how to deal with that particular patient. So they might have a personality disorder, and no-one can deal with them, in which case you try and get rid of them after a while - because you can only put up with them for so long. So you might try and get them to see a different person after a while.
>
> Anna: Share the load?
>
> Caitlin: Mm. Or they've got some psychological problem that you are not really coming to grips with. Or they've got multiple physical problems, and I don't actually classify them as heart-sink. They're more of a challenge really. [Caitlin, late career GP, 10-12-08 p25].

Caitlin expressed a preference not to be in role of weekly health coach, but had adapted her practice to cope with such patients, tending to refer to other people for regular psychological input, but reframing 'multiple physical problems' as actually more complex and therefore more interesting (rather than 'heart-sink'). Caitlin's reframing of the nature of a chronic conditions patient could be a crucial tactic in enabling clinical interest and maintaining partnering relationships, which are necessarily longitudinal. Caitlin recognised the need for different ways of working for some kinds of chronic conditions healthcare, acknowledged that regular psychological support might not be her forte, and referred elsewhere in order to maintain both

her own interest and energy for a particular case, as well as to gain more effective treatment for that person.

This suggests that even when partnering with patients is a strong guiding philosophy and aspiration, each clinician will have a different perception of what makes a difficult patient and find it difficult to partner directly with that kind of patient. Equally, some healthcare professionals will find partnering with their patients a less attractive or instinctive modus operandi. However that partnering may take place in the form of mutual strategizing around appropriate referrals, rather than working themselves with that particular patient.

6.4 Working one step at a time

Another difference participants noted in chronic conditions healthcare is the need to work 'one step at a time'. Kate, who was training to be a health coach as well as a pharmacist, described it as a micro-management approach:

> Kate: So that micro-management approach to chronic health, where you need to make *sure* that the challenge you set someone initially is achievable, entirely, no matter how *insignificant* clinically it might be. I think a lot of health professionals focus on clinical intervention, or clinically significant intervention, whereas in some situations, you've got a lot more work to do before you can actually get to that stage. [mid-career pharmacist, 5-5-11, p5]

She considered that a small positive step achieved by the patients themself was at least as important as 'clinically significant' change instigated by a health professional.

Similarly, Tracy, Caitlin and Brenda specified the importance of small, achievable goals; such as getting weight under 100 kilos (rather than aiming for a target weight of 70kg), planning ringing a specialist for more detail (eg writing a list of things to ask), or giving up one cigarette a day ('which one would you miss least?'). Caitlin suggested that even if you couldn't "see a great deal of change", groundwork for motivation might be achieved:

> Caitlin: [T]hey partly need a psychological state in which they can really be motivated to do something about it. So you have to often work on building up their self-esteem and confidence first I think. And that's the thing, a kind of a, what do you call it, a pejorative approach doesn't do. Because otherwise, if they get treated badly, they won't go and see anybody. [late career GP, 10-12-08 p18]

'Small wins' were considered necessary first steps, so that achieving small goals and maintaining them would improve self-esteem, and thereby self-efficacy. Further goals could then be contemplated with more confidence:

> Brenda: Like someone might say, for example, that they want to give up smoking, but how the hell do you do that, if you've been smoking 30 cigarettes a day? […] Some

> people just can't give up cold turkey. And even with the little chewing gum things they still find it very very difficult - so small goals. 'Which time of the day do you think you could do without a cigarette', 'which has the least impact on you', and they'll say 'well maybe I can't do without my morning cigarette, but the one before lunch I could probably do without'. So you start that way, and once you've achieved that, then you go to the next step. […] It doesn't really matter about the end result. I think, you know, **if they are achieving small goals along the way, then that's a big achievement for them. Little steps to us might be big steps to them.** [mid-career community nurse / DoN, 15-6-09 p5]

It appeared during both observations and interviews that models such as the 'stages of behavioural change' were widely understood and perhaps more relevant than might be found in other more acute care sectors. Terminology would be mentioned in passing in staff education sessions, or briefly overviewed as part of introductory material to more in-depth chronic conditions techniques (for example, chronic conditions self-management frameworks). Staff appeared experienced in assessing which stage of change a patient might be at, and how to 'pitch' their advice towards the relevant stage:

> Tracy: I did do a health promotion or health coaching course – where you go through and assess their readiness to change, and if they're not ready you pretty much just give them the information they need, coach them as to why they should be making changes, and leave the appointment at that – let them contact you when they're ready. [early career dietician, 6-5-10 p12]

Working with a person who was not ready to make substantive changes might include presenting small pieces of information, 'planting a seed' which might shift a person into contemplating change:

> Sandra: I know she's very strong willed and she can only… With Joan, you can plant a seed today, just throw it out there, and she may or may not take it up. But next visit you might say it again, and eventually she might. [mid-career practice nurse/nurse practitioner, 16-9-09 p22]

'Working one step at a time' thus encapsulates an attitude of doing one thing at a time, but also only trying to assist someone to change when that person was ready.

6.5 Working systematically

Systematic care was considered crucial to effective chronic conditions healthcare, with some participants outlining concerns about the potentially ad hoc, fragmented and reactive nature of care. Participants generally responded to their perceptions of such gaps by attempting to create systems (such as recall systems and checklists), for themselves or their immediate teams, in order to alleviate gaps.

One GP had created his own checklist templates (generic but customizable condition management plans) for several chronic conditions, prior to the emergence of computerized

prompts and Medicare rebates. He consequently was unenthusiastic about transferring to the GP management plan formats which were Medicare-rebated, believing their guidelines equivalent or less effective than his own. He did use the suggested psychological health plans formats, which he felt superior to his pre-existing equivalent; however preferred to retain his own processes for managing diabetes and asthma, seeing them as more systematic and comprehensive.

Sandra had worked in intensive care and aged care nursing before going into general practice nursing, and described being used to doing "everything" for each person. In general practice, she had trained to do nurse-led diabetes clinics, and whilst the practice she was in was not using a 'clinic' structure, she was involved in setting up recall systems alongside care plans for every patient with diabetes. 'Clinics' are sometimes held by hospital outpatients, general practice or other community based healthcare centres; and involve particular patients with certain conditions attending at particular times on particular sessions or week days ('diabetes clinic', 'immunisation clinic' and so on). Sandra also planned to extend the system to patients with other long-term conditions:

> Sandra: I look at trying to organise a systematic plan of care – […] whether it's COPD or asthma or diabetes. So that all the things that are meant to happen, like in clinical guidelines, and all the things that make quality patient care are all addressed, and things don't get missed. […]
>
> **That's what really annoys me, the reactive side of things. I want it to be planned and I want it to be systematic, and I want it to be *organised* - so that the patients are coming in, *minimally* every 3 months.** And […] you're doing the regular checks to prevent… – say if I looked at a patient who hadn't had their cholesterol checked for like 5 years, and they were a diabetic patient, and they had risk factors where they could just be a sitting duck for a stroke. Whereas if their care had been *organised* and planned, and systematic, then that wouldn't have gotten missed. [mid-career practice nurse/nurse practitioner, 16-9-09 p1, bold emphasis added]

She wanted her general practice patients to have the same kinds of formalised comprehensive care (and care plans) she was used to from aged care and intensive care work, but found that she was best able to achieve this by creating structures in her workplace herself. While such structures are promoted and encouraged by general practice support organisations, there is no mechanism to mandate this in Australian healthcare at present (Walker, L 2006; Hegney 2007; Walters, Courtney-Pratt, et al. 2012).

Practice nurses within this research varied in their capacity to introduce such systems, and power imbalances between medical and nursing (generally owner and non-owner) staff appeared common. Such findings corroborate previous research (Hegney 2007). Medicare rebated health

assessments are often performed by practice nurses; for example, the 'over 75 years old' health assessment, which may be done by practice nurses in patients' homes. Nikki had recently started working at a second general practice, but felt limited in her ability at her first workplace to change her work content from solely 'task-oriented' nursing to more autonomous forms of practice such as health assessments:

> Nikki: I guess the majority [of my work] at [location 1] is sort of blood tests, and I guess all the people, a lot of people, the majority would be chronic – diabetes, a lot of people with high cholesterol, cardiac problems, chronic wound ulcers, that come in. […] We don't do a *lot* of things at [location 1]. And I feel like… it's just, yeah, it's been good working there, but I could have been used *better*. [mid-career practice nurse/aged care facility nurse, 20-7-09 p2]

To summarize, participants made it clear that being comprehensive and systematic were generally perceived as fundamental to chronic conditions healthcare, irrespective of profession. Participants expressed frustration where they felt that processes or cultures limited their capacity to be thorough.

6.6 Maintaining flexibility

The complexity of chronic conditions, and the individuality of the people presenting with them, seemed to provide some clinicians the opportunity to reflect constantly on their practice ('how can I make this work for this patient'?), and practice in a more flexible way. This was demonstrated by Elise, who talked about experimenting with a wide range of 'tools in the toolkit':

> Elise: I will use anything that comes along, whether it be stages of change[13], or *whatever*, to work out where somebody is, and move in and out of stuff. […] Really, they're all there and they're all very useful, and if you need a battery of tools you can use them. But most of the people we see have lived with their diabetes for an incredibly long time. And you saw with [patient name] today, tried lots of things. [...] So you use all of that stuff, mashed up together, if you need to - or I do - to actually pull [the current issue] out. [late career diabetes educator, 18-4-11, p25]

In such cases, there was a focus on experimentation, documenting the results, and working as a team with the patient to establish what combination of treatments worked best for each individual. This required an easy-going acceptance that patients were doing the best they could, given their particular contexts, and that their 'best' would vary. There was no point in 'beating up' on someone, adding to their guilt about poor self-management of their health; rather it was

[13] A behavioural change theory, suggesting that people "cycle and relapse through five distinct stages:
(1) pre-contemplation with no intention to change behaviour
(2) contemplation and making a decision about whether or not to change
(3) preparation for changing behaviour in the near future, having experimented with behaviour change in the past
(4) action, successfully changing behaviour over a relatively short time
(5) maintenance, successfully changing behaviour over a lengthy time" (Baum 2008, p. 458).

important to establish a cooperative, experimental, buddy-attitude relationship; enabling repeated tries at the same issue from multiple angles.

> Elise: What I've learnt I think, is that **there are no wrong answers.** There's no *right* way of doing anything, or no *one* right way. It's about a journey. It really is about a journey. And as I said to [earlier client], we'll go down a path and if it is not working we'll reverse, we'll get out of there. If we don't get too far into trouble, we can back out. [late career diabetes educator, 18-4-11, p26, bold emphasis added]

Elise represents what many of the participants believed, which was that it was important to have as many tools in the toolkit as possible, but that:

(1) no single tool would satisfy for all cases

(2) it would generally be necessary to synthesize and/or float between multiple tools and tactics as patient responses indicated, and

(3) that fidelity to 'authentic' versions of one tool was generally unnecessary or overrated.

I did not observe or interview a single clinician who felt that one particular method or approach was 'the be-all and end-all'. Participants used tactics learnt from multiple previous work contexts, synthesized into a suite of tactics they could draw on, in working with the multiple issues integral in working with each individual. Where people were passionate about a particular tool (such as a certain CDSM method), they nevertheless acknowledged its shortcomings or inappropriateness for particular situations. The entire cohort thus demonstrated flexibility in this regard.

Another kind of flexibility, other than flexibility in terms of tactics, was demonstrated in a number of observation sessions. I label this 'opportunistic flexibility', in that it involved switching tack from whatever a clinician was doing (in particular what a stated aim of the consultation might be), in order to pursue a 'teachable moment' or apparent 'door opening' with a patient. Sandra demonstrated this during what was should have been a standard diabetic review, by detouring (in response to patient input) to include lap-banding weight management and dietary insufficiency support discussions:

> Sandra: And she has also got a daughter who's overweight, and *she*'s got a referral to a dietician, and as I was *exploring* that idea she said, *she* said it: "Oh, I could go with my daughter." I said 'what a fabulous idea!', and *nurtured* that idea, and led her down that road, where she's quite agreeable. And you know, talking about it. [mid-career practice nurse/nurse practitioner, VTI 21-9-10 p7]

Despite being in the middle of a diabetic review checklist, Sandra diverged to encourage a patient-generated idea (of visiting a dietician). She demonstrated an ability to let go of one immediate consultation goal (update and preparation of a diabetic review care plan), in order to opportunistically pursue a different topic. Her positive reinforcement of a patient initiative also put the patient in the driver's seat (as discussed in Section 6.3 'partnering with the patient'). She

thus demonstrated a commitment to wholism and professional flexibility, by keeping multiple issues 'on the page' during a diabetes review, and not necessarily by expecting to treat all issues by herself (reinforcing patient self-referral). Referring to others also demonstrates flexibility in terms of 'patient ownership'.

Flexibility might also involve taking approaches which weren't necessarily comfortable ways of working. Elise discussed listening out for what she called 'cognitive dissonance', and then taking an approach "*bordering* on confrontation, but not confrontation, […] because nothing is achieved by that" [Elise, late career diabetes educator, 18-4-11, p29]. Cognitive dissonance occurred where a patient appeared to be comfortable with potential consequences, but where disease sequelae were dissonant with other patient goals. Elise described the 'direct approach' as one she had learnt from courses in youth suicide; where, "instead of just pussy footing around the edges, actually saying", naming the complications the health professional was concerned about (in chronic conditions, the disease consequences that if unmanaged would impact on lifestyle goals) [Elise, late career diabetes educator, 18-4-11, p29]. She described the impact that suicide training had had on her diabetes practice; in particular that she now felt empowered to be direct in a way she hadn't previously:

> Elise: I said to a man, after spending probably forty-five minutes talking about complications, complications management, complications screening, et cetera. And it was really just not cooking, quite early on in my practice, and he was about to go. And I shook his hand and said 'thank you very much for your time. And being a taxi driver, I'm guessing that in some point in time, your eyes and feet *will* become more important to you, because I can't imagine you will be able to do your job if you can't feel your feet or if you can't see.' And he said, sat down, just like that, and said 'what do you mean?'. And I thought 'we've just spend the last *hour* talking about your eyes and your bloody feet!'. But he sat, and he un-picked and he picked and he picked, and he dug, and he had it. But it's not somewhere you go, unless you really know what you are doing. [late career diabetes educator, 18-4-11, p29].

This, and Dunc's smoking cessation efforts, were the only examples of intentional scare tactics which were recounted or observed within this research. It is important to note that confrontational approaches were not common, and may be outliers within community based chronic conditions healthcare. It may be that the impact of such attempts far outweighs their frequency, and that such methods are unlikely to be discerned in this kind of partial observation study. Directness in consultations, more than actual confrontation, was an avenue utilised by some participants, as part of a suite of tactics in doing chronic conditions healthcare. Those participants who discussed or demonstrated it, appeared comfortable with its use.

In summary, being flexible and open to patient efforts, opportunistic within consultations, and amenable to using multiple techniques simultaneously or sequentially, were considered crucial by participants to working with people with chronic conditions.

6.7 Highlighting what is going well

Working one step at a time (as discussed in Section 6.4) also meant incorporating regular positive reinforcement of things that were going well. None of the participants specifically mentioned positive psychology (a relatively new branch of psychology, which prioritises study and promotion of optimal functioning rather than identifying and treating 'mental health problems', (Black Dog Institute 2012), or strengths based approaches (Saleebey 1996) as influences. However there was a widespread acceptance of a need to encourage patients by pointing out assets or strengths within chronic conditions journeys:

> Isobel: Build on the positives that we've actually encountered. Yeah, that's really important - building on the positives and *allowing* the positives - and maybe challenging the positives too. […] 'You can do this'. [mid-career community health nurse/health promotions worker, 6-4-09 p18-19]

Positive metaphors ('nibbling at the edges'), and sharing relevant positive anecdotes from other clients, were also considered useful. Whilst the use of positive metaphors and anecdotes to encourage behaviour change is not novel, it is important to note that both played a part in many of the participants' work.

An example of positive reinforcement from a consultation video with Sandra, and her subsequent explanation of it, is typical. Sandra is initially heard explaining preferable diabetes biophysical parameters to a patient, at the same time referring to the patient's specific personal results:

> [Video replay (Sandra talking to patient)]
>
> So we talk about equal to a seven for the HBA1C, and for the blood pressure we're looking at around a hundred and thirty-five on eighty. Which is, one hundred and thirty on eighty. So you're pretty much on track there. […]
>
> [Audio interview recording (Sandra talking to Anna)]
>
> So, what I'm trying to do there is to give her what… to reinforce what is going well for her. Like, she has come in and she is obviously worried about her diabetes management, but by saying her blood pressure is pretty much close to what we had been expecting – I mean, it could be better later on, but at the moment it is quite good. So rather than overwhelming her, and saying 'gotta fix that, gotta fix that, gotta fix that', trying to sort of break it down and trying to say 'look, this is going really well, and we just need to work a little more on here' - so trying to balance up the negative and the positive. [mid-career practice nurse/nurse practitioner, 21-9-10 VTI p4]

She describes being tactical in suggesting that some of the results were 'fine for now', even where they are not as low as clinical guidelines would recommend, and (like other participants)

selectively highlights particular parameters as 'needing work', whilst describing others as 'going well'. Participants described doing this in order to concentrate patient efforts into areas which were felt either more important (for now), or where action could have most effect most immediately. There was an emphasis on creating small successes in order to generate positive feedback, and increase confidence to make changes in other (possibly more difficult) areas.

Being positive was discussed in general rather than specific terms. For example, Elise considered that her work with people with diabetes more about a health and wellbeing framework than a chronic conditions model, similar to other healthcare work:

> Elise: I've worked in midwifery where you are working with women toward a very positive end, I've worked in child health where it's the same thing, I've worked with youth about getting them through things to the other end, worked in diabetes which is about getting through things to get to being confident self-managers. […]
>
> Managing diabetes and bringing that young person along is no different to working with adolescents, it's no different to working with that woman, getting that baby home safely and feeding well, and growing and developing well, really, isn't it. [late career diabetes educator, 18-4-11, p42]

Building on positives could also be enabled through particular activities promoted or undertaken by healthcare professionals. Billie considered walking groups integral to supporting many different people (with and without chronic conditions), but noted that it was only recently that they had been labelled with the department as specifically 'addressing chronic conditions':

> Billie: Social workers were quite integral in establishing walking groups in lots of centres. And of course that addresses things like obesity, heart disease, rheumatism, you know, everything. Social isolation. Pain management. […] So I suppose social workers have been involved in that sort of thing for *years* and years and years without calling it 'addressing chronic disease'. We've never labelled it up. But we've recognised that a daily routine physical fitness helps people on so many levels. [mid-career social worker, 22-06-09 p1]

Reinforcing what was going well, and building on strengths, were perceived as integral to supporting patients' chronic condition journeys; both emotionally and practically – but were sometimes invisible parts of healthcare work. Some participants also used negative anecdotes and metaphors, however did not extensively discuss these as tactics or rhetorics in the way in which they discussed positive approaches (see Section 6.6 'confrontation' example). In re-directing attention to assets as well as deficits, people's emotional journeys could be supported; and by building on agreed strengths, practical outcomes (situational and/or health improvements) could be encouraged.

In some ways, this was about 'visibilizing' and valuing chronic conditions healthcare via small achievements (such as maintaining health status despite progressing disease):

Elise: I guess, it's selling the message 'it's not about numbers, it's about quality'. So things should be goal based or outcome based, not number based - and yet things are number based. [late career diabetes educator, 18-4-11, p38]

Such concerns; that healthcare work was valued largely via measures inappropriate to chronic conditions (such as curative or major improvement goals, rather than maintained status or prevention of episodic decline), or through numbers of people seen rather than improved health status of those participants did see; were periodically mentioned.

6.8 Reinforcing and nurturing independence/autonomy

Participants discussed experiences of enabling, nurturing and having cultural clashes over patient independence and autonomy. In general, participants were active in attempting to establish or maintain patient independence, from the healthcare system as much as from themselves as individual service providers. However they described examples of what they considered 'patient independence' which can be perceived as multiple points on an independence-dependence continuum. Participants described negative patient independence ('won't take drugs', 'won't have an aged care assessment team in', and so on), as well as negative patient dependence on healthcare (system or individual providers). However, maintaining independence was generally prioritised, as in this excerpt from hospital-based participants:

Beth: If you've got somebody in and they can't shower themselves but they can clean their teeth, well, you want them to keep doing that; so they keep that bit of independence - you've got that saying, 'if you don't use it you lose it'. [group interview with DoN and ENs, 5-6-10 p14]

Independence in the community context was also prized, with Tom describing a need to "break dependence" (for example, by extending durations between appointment periods) "as soon as I see dependence building up", and criticizing a previous GP business partner whom he felt was overinvolved with her patients [Tom, late career GP, 22-2-09 p8].

Personal experience, of the joys and difficulties of maintaining independence for elders within participants' families, was also discussed as influential on professional practice. In a two-person interview, Isobel and Martin discussed the kinds of work they like to do, as well as how their personal experience of Martin's mother's dementia coloured their understanding of independence:

Isobel: [I]f people are self-caring, if people were self-determining - if people are empowered to do, you know, have work *doing* what *they* need to do, to be as healthy as they *can* be…

Anna: Then you're happy to work alongside them doing that?

Isobel: Yeah! *Walk* alongside! *That's* what that cultural kind of competence is all about. It's not *fixing* it. It's not making it *better* sometimes. *Not* making it better. [laughs]

Martin: Which is really hard for lots of health professionals, and maybe for nursing in particular. […]

Isobel: Oh, we [nurses] just want to fix it, we want to make it better.

Martin: Well, it's a lot easier to do that - like with my mother, getting her in and out of the car. It's much easier if I just do it myself. But it doesn't… that perpetuates the situation for longer, she's got to exercise and use those muscles. […] And it's precious. Her independence is precious. Everything she can do for herself, she should do. [21-9-10 p15, original emphasis]

Martin and Isobel's view, of "independence as precious", was expressed by most participants. They suggested that the maintenance of autonomy and independence in clinical contexts was crucial, and that *not* doing things for patients unless really required, was key.

While somewhat counterintuitive at first encounter, 'not doing' approaches are corroborated by literature and akin to techniques discussed above in 'being with the individual' (Section 6.2). Some literature suggests that "the less we do the more we give" (Leap 2000 re midwifery), and note the importance of "the art of doing nothing" (Heath 2012 re general practice); alternatively "the excess of doing within contemporary medical practice" (Heath 2012, p. 242). An example of 'not doing things' has already been discussed in 'partnering with the patient' (Section 6.3), where Isobel encouraged Mary to ring the hospital. She noted that this was 'a big deal' for Mary to do (therefore encouraging independence and the possibility that next time the patient might think to do it themselves), but that as a nurse, 'not doing it' was almost harder than 'just doing it'.

Ambiguities in facilitating independence were common, and underscored by a difficult situation I observed during fieldwork with a rural palliative care support team. Participants spent a number of hours in phone calls and meetings, trying to arrange referral, transport and care for a man perceived by some clinicians as antagonistic:

Lauren: [S]omeone whose autonomy and being in his own space, and he hates hospitals, he *hates* doctors, authoritarian doctors. Yeah, we could label him as a personality disorder, but actually this man… just hates hospitals. [late career medical specialist, 12-12-08 p14]

Lauren went on to explain that this particular person's most important concern was for independence, which he defined as non-admission to hospital, in order to stay with his partner and children (including a new-born). For this person, non-admission to hospital took priority over maintenance of mobility (lower limb function). She also noted that the hospital radiography department professionals found this confronting. The in-patient procedure he was threatening to refuse was a radiographic assessment to establish exactly how far secondary spinal tumours had

progressed, and whether he was immediately about to lose lower limb mobility. There was also a possibility of stabilising treatment, with radiation if appropriate as part of the same procedure. However, the patient had expressly stated that he didn't care if he lost all leg mobility, by not going to hospital some hours away and therefore not having both assessment and treatment - so long as he could stay at home with his family. For healthcare professionals used to aiming to maximise physiological/anatomical function, and to 'cure' rather than 'palliate' approaches, this was extremely confronting.

This patient could be perceived as exercising his right to determine the goals of care, after a period of time of living with an illness (significant chronic condition experience). For him, maintaining independence (defined as being with his family and not in hospital) was the primary goal of care; which did not necessarily align with other definitions of independence (retaining lower limb function). Palliative care team members I observed were willing to support him in this, whilst other clinicians (from hospital neurology and radiography) appeared to disagree. Intervening in this kind of cultural clash took considerable time that day on the part of clinicians, committed to prioritising patient goals over apparently 'obvious' clinical 'necessities'. In becoming patient advocates, and potentially thus supporting the patient to 'go against medical advice', they spent time being intermediaries between patients and other healthcare professionals: translators between different parts of the healthcare system. Participants also discussed how they might have to advocate for the health system with such patients. They described planning to have discussions with the patient – but leaving the decision in the patient's hands. Such tactics for dealing with 'difficult' patients echo the reframing of 'heart-sink' patients discussed in 'partnering with the patient' (Section 6.3).

Isobel considered some changes in expectation of independence as not just a kind of historical evolution or progress across the nursing sector as a whole, but rather as distinctly cultural; specific to particular sub-disciplines within healthcare. She described her shock when she worked at a particular rural multipurpose facility, which included step-down hospital beds and residential aged care 'beds':

> Isobel: Yeah, they treated them like… they almost fed them. It was horrible. And showered them. There was very much a… 'this is done to you' kind of thing. [mid-career community health nurse/health promotions worker, 6-4-09 p16]

She noted that a major reason for her shock was the difference in culture to her previous positions:

> Isobel: I worked in a rehab place, and then I worked, my other ticket is intellectual disabilities. And so I worked from a sort of like, 'be your best' kind of context, all the time. And that was in rehab, for people who'd become paraplegics. [mid-career community health nurse/health promotions worker, 6-4-09 p15]

Isobel thus observed that different sectors of healthcare - rehabilitation, intellectual disability support, different community nursing sites and rural hospital nursing - had different approaches or cultures about facilitating the independence of their clientele. Brenda also described present community nursing sector changes as about historical progress as much as specific cultural (community nursing) changes:

> Brenda: Well, it *was* very task orientated. It was more sort of domiciliary, where you would go out and might do 10 showers a day and a few dressings and a few injections. And it's sort of developed over the years to sort of incorporate a primary health care focus, and looking at families, looking at education. And as I said before, the clinical skills of the community nurses have developed as well, in line with the acuity of the clients and the early discharges. So the whole fabric of community nursing has *evolved* as such, and it's still evolving - I mean it always will be. But now there's an ever increasing focus on chronic condition self-management, you know - trying to get people to manage their conditions better, be more independent, be more confident to actually cope with things at home. And as a by-product of that, preventing hospital admissions. [mid-career community nurse / DoN, 15-6-09 p3]

The cultural differences, between healthcare which enabled self-management and healthcare where it was unlikely to be facilitated, were thus considered sector-dependent (by Isobel) and historical (by Brenda). With increasing chronic conditions, and increasing chronic conditions healthcare, participants perceived opportunities to formulate philosophical and practical approaches to how chronic conditions healthcare is done, and considered the prioritisation of independence a crucial aspect. Irrespective of the accuracy or otherwise of their claims, these kinds of anecdotes emphasize the cultural nature of different types of clinical work, and how the cultural nature of the philosophical approaches behind the work influence how the work is done. Cultural aspects of each location of chronic conditions healthcare will thus affect the level of patient independence that health professionals are likely to encourage.

6.9 Working holistically with (or beyond) each individual

Participants were very clear that chronic conditions healthcare needed to address all the complexities of a patient's chronic conditions, incorporating any social and environmental situations which impacted on that chronic condition. I have termed this 'holism', or concern for the whole person: addressing physical, mental and social factors as an interconnected whole rather than solely addressing a disease presentation (Oxford Dictionaries Online 2013). This term is also used in alternative and complementary therapies, and sometimes defined as therapies

which address the 'body, mind, and spirit'. Holism was important to clinicians, who noted that patients rarely presented with 'just one' chronic condition or disease:

> Elise: Diabetes isn't one condition. […] It's somebody with blood pressure, it's somebody with [high] cholesterol, it's somebody who is pregnant, it's someone with renal disease, it's somebody who is an adolescent, it's someone with drug and alcohol problems, it's someone with domestic violence… Diabetes isn't one thing. Diabetes is everything. [late career diabetes educator, 18-4-11, p24]

As outlined in Section 1.2.1, what are medically called 'co-morbidities' are often common patterns of chronic disease manifestation, for example having high blood pressure, high cholesterol, being overweight and having asthma simultaneously. However, participants largely considered the present healthcare system to work against holistic treatment of multiple conditions simultaneously. In some cases they resented having to distinguish between different kinds of care within the one consultation, and therefore simply 'didn't claim' for some services. In others, they found it easier to claim a single Medicare item number per consultation, and claimed for the most prominent consultation characteristic (for example, the length of consultation) rather than for all consultation activities. This means that amounts and patterns of chronic conditions healthcare captured by Medicare data are potentially misrepresentative. This was not just an issue for GPs, but was present across all interviewed disciplines, and speaks to the heart of the difficulties of the present healthcare system in recognising and suiting the particular requirements of healthcare work for long-term conditions. Effects of the present healthcare funding arrangements will be further discussed in Section 7.2.

All the healthcare professionals I spoke with believed that, just as you could not work with only one disease of the multiples present, you could not work solely with conditions independent of their context. Tom explained:

> Tom: They come in, show you a freckle, then say, 'look I'm depressed and suicidal', and you take a big sigh that your day's going to be totally buggered up. And you immerse yourself with that person and that situation. […] Like, you know, a woman who's been seriously sexually abused by multiple people, and incest and so on as a child, and ends up with drug problems, and smokes too much, and heart problems. And gets fat because she likes being ugly and so she's got her diabetes. And her family have all got, by then have all got drug problems, and their kids are all, she's married an alcoholic. And that baggage from childhood has resulted in an *enormous* amount of work for you, because you've not only got her complex health care problems, but you've got all the family and *their* kids. And the next generation. Three generations of problems. And a lot of your time is taken up by that one family, that one group of people. And their physical problems. Everything else flows on from that abuse, from *her* childhood abuse, you've got multi-generational drug, lifestyle, employment, economic, behavioural, schooling, community… problems. [late career GP, 22-2-09i p16-17]

While participants were used to having to deal with more than one issue at a time, the mental gymnastics in keeping track of which issues were being dealt with, by whom, and through which administrative mechanisms - at the same time as actually dealing with the patient - were complicated. Participants emphasized the importance of tackling chronic conditions as part of a constellation of situation, physical and emotional requirements; and wished that the system was less complex in supporting them to do that.

Participants demonstrated a concern for detail (discussed in 'working one step at a time'), however strongly connected details with bigger picture assessments: symbiosis between 'little' and 'big' disease aspects. From noticing a potentially ulcerous foot sore in a person with diabetes and arthritis presenting with a chest cold, ie an 'acute' consultation, to the last minute 'before I go, one last question'; participants noted the importance of staying present in a consultation, alive to opportunity whilst not being overly 'pushy or preachy'. 'Little things' were seen as potentially key to establishing rapport ("any time they present, you think diabetes"), whilst also providing an opportunity to assess function. A practice nurse was observed asking a patient who presented for diabetic review about his dog. I considered this rapport-building, but during our interview she discussed how asking after an otherwise isolated patient's dog not only brought a smile to that patient's face (otherwise somewhat immobile, a potential indicator of depression), but also assessed his capacity to plan and purchase (they had discussed buying a Christmas present for the dog). She noted that if he had a wife she would make a courtesy inquiry about her and assess the patient's social engagement through such an inquiry, and suggested that a courtesy inquiry about the man's dog was equivalent in terms of assessing the patient's mood and 'social' engagement. Such connections, between small details and how they function as indicators of bigger picture health and wellbeing, were frequently observed. At a basic level, participants noted that small problems could slowly escalate if not dealt with. However equally, small problems could be good indicators for bigger problems. Small, poorly healing scratches on feet were described by more than one participant as potentially risky for (or indicative of) someone with diabetes. Participants explained that poor wound healing can cause localised infection of a limb; which can lead to systemic infection (problematic for blood sugar management and therefore longer-term cardiovascular including stroke risks), or with diabetic neuropathy and poor vascularization to gangrene and amputation.

The video-triggered interview with Sandra captured a detailed example of the interconnectedness of multiple conditions, and the necessity of holistic approaches. To Sandra, it was not appropriate

to separate management of Cath's diabetes from physical management of her weight, or from emotional management around her weight:

> Sandra: One thing I don't agree with lap banding - it certainly stops the eating, but the people who have got emotional issues around eating, it doesn't solve those things - about depression, and why you are eating and why are you eating extra, which still keep going when you've had the band done. So she's actually put the weight back on again now. And that could be contributing to her B12 deficiency as well, because there's less absorption with the gut, and what she can eat, and what doesn't make her vomit, and so forth. [mid-career practice nurse/nurse practitioner, VTI 21-9-10 p7]

Sandra needed to take into account multiple physical as well as psychological issues within every consultation with this particular patient. It is possible that this is common to chronic conditions: that where lifestyle and emotional wellbeing have more time to have an impact, they also become more crucial to managing that condition - and thus to doing chronic conditions healthcare.

Holistic practice also meant taking patient realities into program planning as well as into individual consultations. Elise noted that when she first commenced diabetes education work, most of her Type Two diabetic clients were retired. However, now they were mostly working. Their unit had incorporated evening clinics and education sessions, to make it more possible for working people to attend [Elise, late career diabetes educator, 18-4-11, p33].

Primary health care workers noted that people often presented only for acute issue consultations, and felt it was important to be holistic by opportunistically extending a short (acute) appointment in order to deal with chronic issues as well. Alternatively, participants dealt with acute issues as requested, and had patients make follow-up appointments to deal with underlying chronic problems. However, participants noted that this risked inactivity. Elise described a metaphor she had been taught about windows of opportunity in dealing with chronic conditions: of a circle or 'full pie' representing a person's life, including family, work, school, and so on. Diagnosis inserted a new slice into the pie, and in the short-term, people were generally concerned to learn a little, mostly about how to function with an illness. That piece of pie would then shrink as other life events (other pieces of pie) expanded and crowded it out. She therefore, like most interviewees, considered it important to take advantage of every health encounter by being as holistic as possible, in a sense maximising patients' return for effort in attending.

Participants also perceived preventative care as an important part of holistic chronic conditions healthcare. They felt that preventive care of individuals was often neglected, within the apparent urgency to focus on acute issues and 'therapeutic' care of chronic conditions after diagnosis.

Participants perceived preventive care as an important part of post-diagnosis care, emphasizing that potential consequences or deterioration within a diagnosed long-term condition could be prevented or minimised. Elise used the example of her difficulties in finding or funding insulin pumps for children (in some patients, insulin pumps improve HbA1c stability and thereby minimise organ and peripheral circulatory damage), compared with money spent on funding dialysis due to diabetes-induced kidney failure:

> Elise: We will flap our lips, but when it really comes to crunch, when there is no money, guess what disappears off the agenda? We will still be able to buy million dollar *dialysis* machines for the people, but we won't be able to get a [insulin] pump for free for a kid, to prevent them needing it [dialysis] in the future. [late career diabetes educator, 18-4-11, p23]

In summary, participants considered holistic chronic conditions healthcare important - given that patients generally presented with multiple rather than single conditions, that conditions were generally interconnected, and that drug usage for different conditions generated interconnected effects - but that the system generally complicated doing holistic care. Equally, participants felt that lifestyle and emotional contexts and preventative care needed to be prioritised highly, in a way not always be possible within short consultation timeframes predicated on acute condition requirements.

6.10 Working beyond the individual

Most of the participants felt it was important to address long-term conditions at 'system' as well as individual levels. Some of them phrased this as health promotions or public health work, and others also specified health system change as part of their actual remit (or preferred way of working). It is possible that health promotion and public health tactics are highly relevant to chronic conditions healthcare, because some contributing factors to long-term conditions are lifestyle related. While it is hard to say that lifestyle factors are *more* amenable to public health approaches than genetic or biological factors (given that biological factors generally do not express themselves without environmental conditions which enable biological expression), it is clear that some lifestyle factors which impact on long-term conditions can be addressed by population health measures (such as legislation for example, around smoking) and health promotion (such as health education and social marketing). Participants considered approaches targeting populations as well as individuals crucial.

Participants sometimes named this up as health promotion work, where the 'client' is a community, or communities, more than individuals; and sometimes as public health, where

'populations' are targeted. Isobel mentioned actively pursuing nursing work, which specified capacity to take a health promotions role as well as nursing care:

> Isobel: I guess I've, I've always seen [health promotion and community nursing] as connected. *Strongly* connected, not just connected. It's always been… you know…
>
> Anna: Part of your headspace, to look for those opportunities…
>
> Isobel: And to look for work that promotes that sort of stuff. So **I wouldn't be working here if health promotion wasn't part of the role.** In the community. Like, I've worked at other sites where health promotion is seen as, well, that's something you tack on at the end. […] And I don't see that as a really healthy environment for the people that live there. I think it's *not* a tack on. It's something *we do*. [mid-career community health nurse/health promotions worker, 6-4-09 p3, bold emphasis added]

Isobel explained that the remote health service that she worked for had decided to facilitate a particular preventive exercise program to address two local health issues; cardiovascular health and isolation. They were aware that isolation was a problem on the island, as well as a known social determinant of poor cardiovascular trajectories, and chose a program which could address social isolation as well as clinical (cardiovascular) needs. This highlights the integrated nature of her two (officially separate) jobs (health promotion and community nursing): her clinical experience with individuals, as well as research into island needs, determined her health promotion tactics.

Caitlin felt that most of the chronic conditions issues she saw were more public health issues than medical:

> Caitlin: I mean, I think one of the problems is what's in the supermarket shelves. Three quarters of it ought to *go*. And while it's still there they think it's food, and people are going to drink Coke and eat white rubbish and yeah, as much as you tell them they shouldn't be, it's more palatable and tastier and yummier. [laughs] […] So really it is a public health issue in that sense. [late career GP, 10-12-08 p8]

She emphasized the need to work on broader social determinants of health, such as cultural expectations of how to eat:

> Caitlin: [It's] a basic education issue, in that people tend to eat what they've always been brought up to eat. And so changing the way people feed their children has got to be the first thing. And one of the things that's really disappointing is how low the breastfeeding rate is. So that sets actually the pattern for your life long health […], their constitution is kind of set then, and their genetics, so they have to work with what they've got. [late career GP, 10-12-08 p9]

In the end, she saw many of her patients (and herself) as having an unnecessarily and overtly uphill battle with their (partly genetic, partly social) chronic conditions: due to the social factors which impacted on breastfeeding durations and a predominance of poor quality food.

Another type of systematic work, working to 'change the system', was voiced by a number of participants. Many saw their work with individuals as part of working *beyond* individual towards societal needs. As Elise phrased it,

> Elise: [W]e know the goal is really about *money* [savings for the health system]. But you can interpret that to say it's about people staying at work, it's about people staying engaged, it's about people staying with their families, it's about not costing the health care system which means money ends up in the education system or the policing system or something else instead – that's what we all want. [late career diabetes educator, 18-4-11, p34]

While most were not in management roles where structural change to the healthcare system was part of their brief, they viewed chronic conditions healthcare with individuals as part of a need to think about big pictures as well as individual clients. As Maree put it,

> Maree: I really like to work from a system perspective. I like working with people, individuals. But I really feel that where we need to work is with changed structures, so I guess my value set is in challenging some of the structures. [late career psychologist, 9-05-12 p17]

6.11 Taking the time

Time was possibly the crucial issue in attempting to work with people with chronic conditions. Holistic work in particular was perceived as time-consuming, not necessarily in a negative sense, and not something that could be rushed. Longer consultations were preferred by many participants, and considered necessary for practise with depth (as well as breadth). Participants felt that this needed to be both accepted and planned for in advance, and demonstrated a variety of tactics in time management. General practitioners had patients book longer consultations, or more frequently during seasonal 'bad times'; community nurses allowed longer visiting times if they were aware that clients had complex needs; and occupational therapists discussed ensuring they had a mix of 'straightforward' as well as complex clients on their list so as not to run out of time each day.

Caitlin was typical, and felt that in order to work in the way she preferred she could only book four patients per hour (rather than six as some of her colleagues did). She did feel that this was going against the peer culture within that practice to some extent, but justified it as less superficial practice:

> Caitlin: I mean, you can do it in a more superficial way or you can do it in a more… I just find it wouldn't be very satisfying to do it in a very superficial way, you know? - 'come and sit down, what is your blood pressure, right you need this tablet, see you in two weeks' - that's only half the story isn't it really. […] I mean, I don't know

> how many doctors really find out which of their patients eat wrongly and don't exercise and *don't* relax and work too hard… [late career GP, 10-12-08 p11]

Caitlin also voiced a concern that when not enough time was spent in a consultation, the patient would have to return sooner in order to deal with other or related issues which couldn't be covered during shorter consultations. She felt this inconvenienced patients, particularly those who were remote to her rural location, who were working and had to take time off for consultations, or who were carers. She also implied that she felt it was sometimes poor medicine:

> Caitlin: What I find those people [who] do book like that, is that they will see patients much more often. And they are mostly seeing everybody every few weeks. Whereas I don't work like that myself. You know, a lot of drugs for chronic conditions have six months' worth of prescriptions; so I often, if whatever their problem is, is well controlled, I won't see them for six months. [late career GP, 10-12-08 p23]

She considered seeing patients frequently both tiresome for the patient, and exhausting and uninteresting to her as a health worker. In order to maintain her motivation around working with these kinds of patients, she preferred to see them less frequently, but deal with them in a more detailed way at each visit. Another GP participant had shifted to minimum half hour bookings for chronic conditions patients, and said it had enormously helped in having the practice run on time.

Other participants also endorsed this predilection, considering longer consultations as more efficient in the long run. Elise described a study which she had participated in (into use of time in child health in a rural Tasmanian location) as part of her rational scaffolding for long consultations:

> Elise: There were girls [nurses] that would put through a lot of people in a day and they were banging their drums about 'I've put through so many more people than they do'. But when they actually looked at it, the girls that were spending forty-five minutes with a mother and her baby, actually saw that woman *many* less times, but had the same outcome, as those girls that were seeing them in fifteen minute slots, every week, over the same period. So it's recognition of that, I think, that chronic disease, sometimes, there are *aspects* of it where you can do it in 'short and sweets'. […] [But] using other models, and other tools, needs to be really recognised, but also validated. [late career diabetes educator, 18-4-11, p39]

Others considered that taking more time in consultations had made them better practitioners than earlier in their careers:

> Brenda: I find I am a better listener, than I was before – you know, before I'd think, 'oh, come on, hurry up I've got to go, I haven't got time for this'… But now I take time to listen - or if I really *haven't* got time, I'll say, 'well I've got another appointment now but I do want to listen to you, can we continue this conversation when I come back next time? Or can I ring you and we'll talk about it further' - that sort of thing. It just shows them that you *are* actually interested in them and what they have got to say. [mid-career community nurse / DoN, 15-6-09 p21-22]

The prevailing sense was that taking the time to listen to and validate patients' experiences, and to deal with multiple complex issues within one session (rather than greater numbers of short sessions), was better practice.

Valuing longer consultations as better practice actually determined some participants' work choices. Heather discussed interviewing for jobs at two different general practices, and selecting the practice which did not emphasize 'running to time' during the interview. Isobel had chosen to work as a drive-in drive-out worker in a more remote area, rather than a regular commute to a close rural area, in order to diminish time pressures within consultations:

> Isobel: That's why I choose to work out here. I've worked in urban areas, and it's a very time contracted, ah, experience, with the patient. And I don't think it's…You're in for a tight period. *You are on a clock*. In an urban setting. But you've got twenty people you need to see, and *you are on a time piece*. You are just pah pah pah pah [breathy puffs], in and out, and it's just like… They want to *talk*, they want to *express* how this is impacting on their lives, and there's *just* no, no *room* for it! [mid-career community health nurse/health promotions worker, 6-4-09 p7]

She felt that, even in the rural location where she had worked previously, time pressures were considerably more than those in her present remote location. She considered this was detrimental to the kind of chronic conditions healthcare (in particular self-management support) that she believed most effective and wanted to do, and selected workplaces where she could manage her own time to a greater extent.

I suggested to Elise that sometimes structures didn't *allow* people to take time, irrespective of their working preferences. She responded pragmatically:

> Elise: [pause] We probably *make* time, in diabetes. […] I'll be here till seven o'clock tonight if that's what needs to happen. But that's because I'm old, and I've been around a long time, and I was in management for a while, and I will tell people [management] to get back in their box. [late career diabetes educator, 18-4-11, p38]

It appeared that participants not only considered it important and more efficient to have longer consultations, but that a willingness to 'take time when it was needed', was one of the defining characteristics of clinicians in this study.

6.12 Summary

In Chapter Six I have described tactics and techniques participants used and discussed as characteristic of, and central to, chronic conditions healthcare. In this chapter I explored what it is that health professionals are actually doing, within the wide-ranging catchphrase 'chronic conditions healthcare'. Participant descriptions and research observations of such techniques give important insights into how chronic conditions healthcare is done, and the different nature

of chronic conditions healthcare, in particular regarding the practitioner-patient relationship. Approaches described, while not exclusive to chronic conditions healthcare, may flag the presence of chronic conditions healthcare, and, when utilised in chronic conditions healthcare contexts, have distinctive presentations. Particular kinds of patience, perseverance, and willingness to 'keep giving different things a go' appeared to constitute a commitment to individual patients, which were intended to shift the balance of power towards patient-determinations of overall decision-making about and delivery of interventions.

For participants, healthcare for an individual with chronic conditions meant opportunities to focus on the lifestyle and emotional conditions surrounding that individual that could impact on their long-term conditions, in ways in which they might not have time (nor relevance) to pursue in acute injury or illness scenarios. Participants also considered both individualisation and holism crucial to chronic conditions healthcare; frustrated with systems which expected them to isolate different conditions and treatment regimens from each other, and to deal with individual patients independent of their social and environmental contents.

With Chapter Five establishing *what* chronic conditions healthcare might be, Chapter Six examined *how* chronic conditions healthcare is done. While it is not easy to give separate attention to chronic conditions healthcare, given that it presently exists only within other more formalised (or 'branded') kinds of healthcare work, this chapter makes some preliminary moves in that direction. In Chapter Seven I will investigate some contexts which shape the experience and doing of chronic conditions healthcare.

7 External Factors Influencing Chronic Conditions Healthcare

7.1 Introduction

At present in Australia (and Tasmania), contextual factors affect how individuals practice. Socio-cultural and environmental conditions sometime enable or make possible good chronic conditions healthcare (for example: good continuity of care between community and smaller rural hospitals, longterm patient-professional relationships enabling deeper knowledge and more effective advice). However, socio-cultural and environmental conditions sometimes also constrain chronic conditions healthcare (for example: time pressures within general practice consultations, limited autonomy for some professions, personal antipathies or 'triggers' within particular patient-professional relationships). Factors which enhance and/or subdue chronic conditions healthcare are the foci of this chapter, as well as of the original Research Sub-Question 1: 'what are the issues for such health professionals in doing such work?' The results and analysis in this chapter continue the work begun in Chapters Five and Six to address Sub-Questions 2 and 3: 'what are the strengths of such health professionals', and 'what are the strengths of chronic conditions healthcare itself?'. Chapter Seven demonstrates that, for chronic conditions healthcare as in other kinds of healthcare work, external factors (including the present invisibility of chronic conditions healthcare) shape the style and type of chronic conditions healthcare that clinicians do.

My assumption, as befits a social construction perspective, is that micro, meso, and macro-environmental and social conditions both constrain and facilitate chronic conditions healthcare. However, this chapter highlights those factors which participants considered most influential. I structure this chapter by examining the effects of macro, meso and micro-level zones of influence on chronic conditions healthcare (further issues raised by participants are provided in Appendix 7). Section 7.2 'Funding' represents macro-level environmental conditions, and Section 7.3 'Role' represents socio-cultural conditions. Equally, 'role' is used as a signifier of the complexity currently present within healthcare, wherein every discipline represented in this research could form a separate chronic conditions healthcare case-study. Section 7.4 'Personal experience' incorporates the sometimes-neglected micro-level climates, which influence and construct every individual's particular practice of chronic conditions healthcare. These particular factors and

influences were selected from the variety of related themes raised by participants, as the most important and representative of the broad range of external influences raised by participants and covered in relevant literature.

7.2 Funding

Funding models were of concern to many of the professionals I spoke with[14]. While funding models clearly are designed to enable and even increase chronic conditions activity, participants largely spoke of funding models as constraints. Concerns were not primarily with limited funding, although concerns were expressed about this, but rather with the structuring of funding, and how this impacted on capacity to practise in the ways people wanted to. Elise expressed her frustration:

> Elise: It's *really*, it's *bashing* your head against a wall most of the time. [pause]. We work in an environment where the funding models are all *wrong*, the health, the hospital model is all *wrong*, pathways in and out of things are all wrong, training is all wrong. So it's *rhetoric*. And it's *burnout* territory, if you really believe in it. [late career diabetes educator, 18-4-11, p23]

In this sense, funding distress represented larger concerns about the kinds of health models which practitioners and patients felt forced to participate in. In particular, people found it frustrating where they wanted to work in health-promoting or health promotion-based ways (illness prevention) with either individuals or groups at risk; but were only funded to work with such people subsequent to the presence of a particular disease or illness. Participants regularly discussed funding logic, inflexibility, and social or professional closure around payment structures; as impacting negatively on long-term conditions work.

7.2.1 Funding logic

Participants generally expressed a perception that funding is presently predicated on acute illness models rather than long-term condition models. By this they meant that patients needed to have suffered an acute event or disease crisis, and to be symptomatic, in order to access government funded treatment. Funding logic was understood as 'fee for service payments based on an acute model determination of service need'. This is reinforced by the present structure of Medicare (Australia), which is 'fee for service', with payments are generated by numbers of service encounters and procedures or interventions (Williams, L 2005, p. 365).

Indeed, for some health professions (such as dietetics, occupational therapy, and physiotherapy), it appears almost imperative for a patient to have an acute or 'new' diagnosis in order to access

[14] While some participants construed factors such as 'health system structure' to be more important than 'funding', this analysis uses funding as a pragmatic window into both funding and structural concerns.

government funded care. Participants noted that with fee for service payments, patients are encouraged to put off visiting their primary healthcare professionals until 'a visit is necessary' (eg an acute exacerbation of a chronic condition arises); as opposed to treating visits to healthcare professionals as insurance against becoming unwell. In many instances, this means patients are seeking help at a later stage in their illness, when their condition is no longer (or less) amenable to lifestyle changes and only able to be treated with more intrusive interventions (such as medications, which, while less intrusive on daily life for many than major lifestyle modifications, generally have side effects which may also need pharmaceutical intervention: beginning a 'cascade of interventions'[15]. While part of this may be considered to be about cultural norms in help-seeking, participants also considered funding structures disadvantageous; in particular, the current inability for patients to regularly access free or cheap preventive healthcare.

This was particularly clear in the case of community nursing, where an acute event might bring a client to service attention, but consultation time was needed for other things. I asked Kathleen about her work with one particular patient we had visited that day:

Anna: So in some senses you're not funded to deal with his chronic conditions, but…

Kathleen: No, we're not.

Anna: But that's what you spend the majority of your time today doing?

Kathleen: Well, look at how long we talked today, about his pain. […] And it didn't take me long to do his wound-care, did it? [mid-career community nurse, 11-6-09 p1]

The consultation time had mostly been spent on chronic pain issues, during and after dressing a wound, and this example was typical of others observed and discussed with other participants. Most participants noted that they 'take on' patients for acute issues, but spending the bulk of consultation time on issues resulting from chronic conditions. This was considered typical by all the generalist healthcare professionals observed and interviewed.

Some participants described wanting to have patients visit regularly (for example, three-monthly) irrespective of whether their disease process was 'active' or not, in order to build and maintain relationships which would facilitate better treatment when things were worse. They also suggested that disease monitoring, education and activity, at times where patients might have better physical and emotional capacity to take information on board and actually make changes, were preferable to periods of absence followed by periods of intensified contact during periods of un-wellness. Consultations when people were symptomatic were described (and observed to

[15] midwifery term, referring to the potential (some say increased likelihood) for further medical interventions after an initial medical intervention is commenced.

be) largely 'functional' and reactive - about symptom relief and management more than relapse prevention. Participants described wanting to assist with status maintenance and condition improvement, in a way which was not possible during acute exacerbations. Three monthly visits were sometimes enabled by requirements for new prescriptions (motivating a visit to a GP), or by other acute conditions which required regular health system access (such as wound care), during which time other long-term health issues (such as diabetes and its effects on wound healing) could be discussed. However, this kind of chronic conditions healthcare was perceived as opportunistic rather than systematic, and inherently ad-hoc. There was a sense that *if* funding models were based on normal (predictable) chronic conditions trajectories, rather than on models derived from acute 'fixable' conditions and based on single service encounters, that the process of working with patients could be different.

7.2.2 Funding inflexibility

A second concern was the inflexibility of funding, particularly as a result of 'siloing' of state and federal healthcare, which the participants considered inappropriate to the normal complexity[16] of chronic conditions. Chronic conditions, as discussed in Chapter One, do not sit neatly within specific silos of organ specialties. In addition, different elements of particular conditions are dealt with by specific federal *or* state funded healthcare sectors, meaning that a patient needs to visit multiple services in order to get treatment for one condition. Diabetes was often used by participants as an example:

> Elise: [B]ecause diabetes is not just one thing - it's podiatry, it's nutrition, it's education, it's endocrinology and so on - you might need quite low level care for your feet, but quite high level care for your kidneys or something else. So one person might be trying to traverse different services. So there's confusion and difficulty for the client *there*. Also getting *between* services. [late career diabetes educator, 18-4-11, p40]

The preference was for funding (and records) which could follow a client seamlessly through different levels of healthcare, rather than separate funding silos (records, assessment processes etc) for each level of healthcare (community-based, hospital-based, preventative - ie state, federal, and local government-provided healthcare). Research participants struggled to create 'workarounds' which matched clinical need with existing funded services:

> Elise: If we see somebody [who has] come into hospital because their diabetes is unstable and we started their care, but now it's relatively stable, now they belong further down in the tiered model: we [the state service] can't refer! Because they're funded through the Commonwealth. And for the Commonwealth to actually provide a service, they have to get sent a care plan, through the GP, so we've got to refer this person back to the GP […] to get a referral and to get on-going care. [late career diabetes educator, 18-4-11, p39)]

[16] Complexity will be further discussed in Chapter Eight.

Participants were frustrated that normal presentations of chronic conditions, the 'natural history' of such diseases, were not accounted for in present funding allocation mechanisms. Multiple diagnoses ('co-morbidities'), patient trajectories through different "ages and stages and phases" within conditions, and patient needs to move between different services were not presently supported by the funding models. Professionals, as well as patients, are thus expected to navigate an increasingly complex happenstance of funding buckets and service outlets:

> Elise: [T]he difficulty getting between aspects of the service because of funding models. We get funding, that comes down in particular pockets, that's inflexible. […] So there's all this policy and rhetoric, *none* of which actually looks at the reality… – we would *do* better if we didn't keep bumping up against walls, we do sneaky things and go around walls, all the services do, but there's so much 'workaround' […] - we wouldn't do workarounds if we could get the wall out the bloody way. [late career diabetes educator, 18-4-11, p40]

A further concern was the inflexibility of funding in regards to preventative work; that is, the limited (or non-existent) funding available to intensively service people who were 'on the road' to a chronic condition but not yet actually meeting diagnostic criteria (for example, overweight but not obese, glucose intolerant but not diabetic, or high blood pressure but not high enough to medicate). The concern was that funding was tied to actual chronic condition diagnosis, rather than to diagnosed risk factors or predilection for particular disease pathways. Sandra was frustrated she could not work with patients *at risk* of chronic conditions (prior to actual diagnosis, at a stage where lifestyle modification is most likely to be most effective):

> Sandra: Because in general practice it's a private business; and if you see a patient and I can't charge an item number […], if I can't make this job financially pay for itself, then I feel pressure from within the practice to justify my role here. And if I can't charge an item number… And **that is why we haven't been able to focus on the preventative things, and risk factor lifestyle change, because at the moment there's not an item number for Medicare to address it.** [general practice nurse / trainee nurse practitioner, 16-9-09 p2, bold emphasis added]

She discussed the importance of the Medicare-rebated visits for general practice nursing for people with chronic conditions, in the context of a nurse-led diabetes clinic within a rural general practice. Care plans for every patient with diabetes enabled Medicare payments for visits to a practice nurse, as well as reduced-cost visits to allied health professionals. However, again, participants were concerned it was necessary for people to have a specific acute ill-health event (such as a heart attack, diabetic crisis) in order for them to access maximum funding and treatment options. It was very difficult for the equivalent amount of money to be accessed in order to prevent such an event, even when that event was statistically predictable:

> Elise: We will flap our lips, but when it really comes to crunch, when there is no money, guess what disappears off the agenda? We will still be able to buy million dollar

> *dialysis* machines for the people, but we won't be able to get a [insulin] pump for free for a kid, to prevent them needing it [dialysis] in the future. You can put in a stent to somebody, that will keep them alive for another three to six months - but we can't give a pump to a kid. [late career diabetes educator, 18-4-11, p23]

The funding is thus generally only enabled for a patient at a relatively late stage in their disease prognosis, rather than at an early stage where it might be possible to reverse the onset:

> Elise: We have people with impaired glucose tolerance, who don't fit anybody's model anymore - the people that we should be focusing on, the pre-diabetes people, don't fit anyone's model.
>
> Anna: They don't get any services at all?
>
> Elise: Pretty much. Oh, Diabetes Tas do a little bit of stuff round the edges, I understand, because they, like us, realise that's not ok. People with gestational diabetes - they have pre-diabetes. They need lifelong care and support. [But if] they don't have diabetes, they don't fit anybody's model. [late career diabetes educator, 18-4-11, p40]

Money was available for medication and specialist visit rebates post diagnosis, but limited or non-existent for regarding anything pre-diagnosis. Health promotions money was understood to be targeted at groups rather than individuals, and referrals to visiting diabetes educators, dieticians and physiotherapists (three monthly in some communities) already had full waiting lists of people already diagnosed. Participants were concerned that people at risk, needing intensive lifestyle intervention or other forms of preventative healthcare, could not be seen in a timely fashion. They wanted more money put into preventative services, whether delivered by themselves or by others.

7.2.3 Funding paradigms in the form of care plans: social closure

To some extent, participants viewed 'care plans' as a mechanism for limiting Medicare rebates to those professions and tasks which had been allocated specific item numbers. Most participants who were not medical professionals were dependent on GPs as gatekeepers for access to Medicare payments (via a care plan, rather than directly having item numbers themselves). Sociologically, this can be described as a process of social closure, a kind of professional corralling of resources or resource allocation. Even where Medicare funding for non-medical services was enabled, participants did not always feel that as many referrals as might be appropriate were generated, or, in some cases, that referrals came early enough to maximise assistance to patients.

Even when resources were stretched (demand for one region's rural hospital outpatient dieticians' appointments was described as 'doubling between 2006 and 2010'), participants felt that early referrals to appropriate services had the potential to save healthcare spending further

down the track. Having to get patients seek medical referrals in order to access subsidized care, in some instances delayed or decreased likelihood of patients receiving expert chronic conditions care. The specificity of Medicare item numbers to particular professions, as much as to delivery of particular services, thus appeared to impede capacity for some highly motivated non-medical professionals.

To be fair, policy attempts have been made to address this: in 2005, early in this research, Medicare introduced further new item numbers (codes for payments) for Chronic Disease Management (subsequent to Enhanced Primary Care item numbers, Practice Incentive and Service Incentives Payments)(Swerissen & Taylor 2008). All three GP participants were unimpressed by the additional care plan item numbers, and concerned that they were wasting 'valuable clinical time' converting pre-existing patient information (including referrals to other health professionals and pre-existing or implicit care plans) into formats which were Medicare funded. Even where they felt that such time was reimbursed, they felt concerned that clinical time was taken up by what they saw as 'jumping through administrative hoops' (see Tom, late career GP, 22-2-09i p14). This was particularly felt in smaller practices, where administrative processes for care plans were not outsourced to nurses or reception staff.

Tom believed that the time pressure he felt, as a solo rural GP, did not allow him to do care plans in the format required for Medicare payments. He clarified that it was the process of contacting the other healthcare providers to be listed on the plan which was most time-consuming (requires verbal or other contact as well as a referral letter):

> Tom: Say you've got someone, a kid who needs speech therapy, and they can get six sessions if I do a complex care plan. If I'm going to do one and I'm going to do it honestly, that means getting *three* people, three people involved - and if you do it really how they want you to do it, and you're not in a big conglomerate, it takes me more time and effort to do that chronic care plan than I could bear. And I *haven't* got the time. I'm *out there* delivering medicine. **I've only *just* got the time to give a service to the community in acute medicine and chronic care my way, as best I can. I *have not got time* to do a chronic care plan. Cos what they get out of it, at the end of the day, is - not - worth - my effort. I'd rather just say 'yes, your kid needs speech therapy, here's the referral' - it would only take me ten seconds to get the same result.** […] I'm not going to put two hours of my time, whatever it is, sometimes more, into doing what the thing was set up to do. It's really a good thing, a chronic care plan, it's supposed to help and that's what it should be, but it's been mutated, Australia-wide. [late career GP, 22-2-09i p14, bold emphasis added]

Two of the three general practitioners described not using the newer item numbers or Medicare format care plans in cases where the patient would have been eligible: one 'never', because they

did not consider the Medicare care plan templates particularly useful or effective compared to the existing templates they were using; and another irregularly because the practice they were working for was not set up to facilitate such. None of the GPs felt that Medicare format care plans had substantively changed their chronic conditions practice or their numbers of referrals to allied health professionals:

> Caitlin: And the sort of stupid red tape type demands now – like, you know, these stupid *care* plan things! […] **[Y]ou are just writing these kind of mickey-mouse things in the templates anyway, just for the sake of having to produce a document**. […] I mean you could write a really long and detailed one if you sat down for half an hour and did it - when *they* [patients] weren't talking at you! [laughs] […] But the thing is, it's what I've always *done*. I've got it in my head anyway. I've got it in the file - in the notes, 'see the dietician', 'see three months', this this. What their BMI is. What it ought to be - it's all *there*. So it's not doing anything except just producing this bit of paper. [late career GP, 10-12-08 p30-32, bold emphasis added]

It is uncertain if the six general practice participants represent only a small subset of broader general practice views; however, dissatisfaction with care plans was a prominent concern for all general practice situated research participants.

Some practices I observed had practice nurses write care plans, which GPs 'signed off'; thereby accessing additional Medicare payments for creating a care plan, as well as Medicare payments for practice nurses. Sandra, a practice nurse, described the process:

> Sandra: So the management plan that I am doing here in general practice is more about, um, coordinating all the data of the Medical Director [general practice software] file into one document. It's not putting, it's not me making a separate judgment on how to treat something – it's more bringing together everything that is there, and putting it in a plan. So **I'm not actually making any new decisions, I'm just putting it into one document**. [mid-career practice nurse/nurse practitioner, 21-9-10 VTI p17, bold emphasis added]

Tom described this kind of work as encouraging a "chronic care plan industry" [Tom, late career GP, 22-2-09i p14], where existing information and referrals were converted into a different format approved for an additional Medicare payment:

> Tom: [A] lot of vast practices very openly use chronic care plans as an income generator, primarily – […] 'all the doctors are doing that cos we can get people through in twenty minutes and earn $180'. And that's just transformed into their focus - they're not interested in the outcome, so long as the doctor can sign off on the chronic care plan. [late career GP, 22-2-09i p13-14]

He was, however, enthusiastic about mental health care plans, because they enabled better access for his patients to psychologists:

> Tom: I think the opening up of Medicare to psychologists is the single *great* advance in Medicare since Medicare came onto the scene in the late seventies, middle eighties whatever it was. To me, that has revolutionised access to health care, whereas a lot

> of other things that happened have *limited* the access to health care. [late career GP, 22-2-09i p14]

Participants did not appear concerned about *who* (which profession) did particular kinds of chronic conditions healthcare, but were generally more concerned that chronic conditions healthcare should be done well, 'properly', rather than in a token manner. However mechanisms to enable referral between professions / sectors appeared fragile: for example, Brenda discussed the capacity of her community nurses to undertake chronic conditions self-management support/facilitation (having been involved in research projects and trials of self-management tools), but noted that she had never seen a GP in her area refer a client to community nursing for chronic conditions self-management. Nursing participants did state that they felt that they had more time to give to individual patients than they perceived GPs to have; and also that, despite specific care plan item numbers, doctors were not necessarily funded to do the management of chronic conditions. Brenda also drew a distinction between funding for 'creating' a care plan and funding for 'management' of chronic conditions:

> Brenda: I don't know whether they actually get specific funding for the management of chronic conditions - I know they do for their care plans. […] Yes, and GPs just don't have time. That's why I think that it's good - if nurses can do it [chronic condition management], why can't we get a referral from a GP, or another health professional? [community nurse / DoN, 15-6-09 p16]

Brenda's concern regarding limited GP time was independently supported by one GP, who described Medicare as problematic for chronic conditions healthcare in general. Heather felt that the lower reimbursements for longer consultations disenfranchised GPs who took on patients with complex chronic conditions:

> Heather: The Medicare system is certainly not set up for it [chronic conditions healthcare]. That goes back to money, and income. [eg] Most of my consultations seem to be C or D levels, which are the longer ones. Any consultation between 5 and 25 minutes, 20 minutes or something, is a B level consultation. So you could do lots of ten minute consultations and get paid, I don't know, I've no idea what it's worth, say thirty dollars per consultation. But you do a D level, which is greater than forty minutes, and you only get sixty dollars or something. [mid-career GP, 16-12-08 VTIii p17]

She emphasized:

> Heather: I really feel if you were money-focused, you wouldn't do chronic conditions stuff. Or, you'd do very little, or you'd have a practice nurse who did most of it – and then you'd just see the patient to write out the scripts in the end. [mid-career GP, 16-12-08 VTIii p17]

Despite her perception of present financial disincentives to doing chronic conditions healthcare, she specified her personal commitment to being paid less but working in the way she preferred.

In this, she voiced the concern of many of the participants, who felt that they were taking pay cuts in attempting to do more and better chronic conditions healthcare.

Allied health professionals felt similarly about Medicare to GPs and nurses. They were concerned that, with limited consultation numbers annually (five subsidized visits via care plans) shared across multiple allied health professionals, their capacity to support people with chronic conditions was limited. Maureen, a physiotherapist, talked about preferring to help people's lifestyles more than simply treat their joint: "I'm more interested in people than I am in conditions" [Maureen, late career community physiotherapist, 3-5-10 p4-5].

Some allied health participants specifically mentioned preventative healthcare work, but did not see themselves as funded to do it. Kate, a pharmacist, was not enabled to access Medicare payments even if listed as an involved health professional on a care plan, as there is no present capacity for a pharmacist to be part of a chronic conditions care plan.. She could be paid to do chronic conditions healthcare via a 'Home Medication Review' or 'Residential Medication Review' (both of which have Medicare item numbers), however not for ongoing medication advice and lifestyle management suggestions provided at the pharmacy itself.

Kate noted that most pharmacists considered preventative health not within their scope of practice, "linked to the fact that there hasn't been a lot of remuneration associated with that" [Kate, mid-career pharmacist, 5-5-11, p4]. This was despite her observation that community pharmacists were in a great position for early intervention and illness prevention advice, in that 'every sale was a health promotion opportunity'. With preventative health work not remunerated within the present pharmaceutical payment structures, she felt pharmaceutical work was limited to "end-stage" activity:

> Kate: Well, to me, obviously as a pharmacist, our core activity is optimum use of medicines and quality use of medicine. [T]here's the whole home medication review process that pharmacists are involved in, with people with large amounts of medications and chronic conditions. […] But to me, that's a bit of an end stage approach, in that a person in a lot of cases can't really *affect* the medical situation they are in - if they've got diabetes and they're a hundred and thirty kilos, then chances are, it's going to be an uphill battle. [mid-career pharmacist, 5-5-11, p5]

She was concerned that the only funding she could access to assist people was for people with well-entrenched chronic conditions. For this issue, her 'workaround'[17] was to train as a health coach, in order to be able to access Medicare payments to work with people in earlier disease

[17] 'workaround': phrase used by another participant (see Elise, Section 7.2.2), to indicate ways of getting around administrative restrictions to deliver care as the health professional saw fit.

phases. By attaining and using more than one healthcare professional qualification, she planned to bypass the social closure presently enforced on her pharmacist role.

To summarize, as demonstrated by participants' experiences of care plans, item numbers and workarounds; funding logic was perceived to be based on acute care models, and insufficiently flexible, effective or appropriate, for chronic conditions healthcare.

7.3 Professional Identity and Roles

Whilst the multi-profession focus of this research does not allow for a detailed consideration of how different professional identities affect chronic conditions healthcare, the data does suggest that different healthcare professions are constructed and situated differently, and thus may construct chronic conditions healthcare in different ways. The differing formal responsibilities of doctors, nurses and allied health practitioners, and the situated nature of practice are examined below through discussion of roles.

Sociologically, the concept of 'role' describes the determination of behaviour *via* occupancy of particular social and/or professional positions (Abercrombie, Hill & Turner 2000, p. 301): with "the dynamics of professional identity involv[ing] overlapping and interacting between personal, social and collective identity" (Van Galen 2013, p12). Professional roles and cultures (actual and imagined) develop over time, with individuals taking on influences during their undergraduate training and career trajectories, and cultures evolving "language, custom and convention" (Abercrombie, Hill & Turner 2000, p. 83) within particular professions or even specific workplaces, over time. Some sociologists distinguish 'social structure' from 'culture'; where social structures are social institutions, and culture is "a kind of social cement keeping the structure intact" (Abercrombie, Hill & Turner 2000, p. 83). Anthropologists generally use culture as "a collective noun for the symbolic and learned, non-biological aspects of human society" (Abercrombie, Hill & Turner 2000, p. 83). For the purpose of this research and thesis, I use 'culture' as a 'collective noun' rather than as 'social cement'.

Roles can be quite generic ('doctor', 'nurse', 'parent'), or more particular ('community social worker', 'hospital physiotherapist', urban or rural pharmacist). In this research, it appeared that people's roles (as well as environment) significantly determined how they did chronic conditions healthcare. Different professions, and differentiated roles within each profession, approached chronic conditions healthcare in different ways. There were clear commonalities between practice nurses for example (in contrast with an oncology nurse, rural hospital nurses and diabetes

educators); between the allied health professionals to some extent; and between GPs. There were also strong commonalities between the nurses and the diabetes educator participants: unsurprising as diabetes educators generally train as nurses first, and then do postgraduate qualifications to specialise in diabetes education[18]. However for all nurses interviewed, their earlier nursing paradigms were clearly influential: for example, mentions of midwifery and child health by a diabetes educator, of remote Aboriginal primary healthcare by a community nurse, and of intensive care by a trainee nurse practitioner.

While I do not subscribe wholly to a kind of professionally-based cultural determinism, the backgrounds, trajectories and working locations (situated nature of practice) of clinicians need to be better considered in terms of how they affect the doing of chronic conditions healthcare. Interestingly, in contrast to 'funding' where most participants felt it largely a constraint, most participants considered 'role' both a constraint *and* a facilitator of their chronic conditions work. The second half of this chapter looks at role as a facilitator and constraint; then at how individuals attempted to shape their roles (situationally negotiate role scope) to do chronic conditions healthcare.

7.3.1 Role as a facilitator of chronic conditions healthcare

The role of diabetes educator was the only role within this research which specialised solely in work with people with chronic conditions. It thus provides clear (although outlier) example, of how a designated rather than generalist role can facilitate chronic conditions healthcare. Whilst disease-specific (and thereby limited in potential application to other diseases which are less biologically encompassing in their effects), the existence of such a role demonstrates the capacity of the health system to provide services specifically aimed at people with chronic conditions. It also provides a potential model for chronic condition specialisations within particular professions.

One particular attribute of this role was the breadth as well as depth of practice it encompassed. Elise felt that the role of diabetes educator was the first to utilise the full range of her nursing experience:

> Elise: It is a kind of a place where all that stuff comes together. It is just quite the extraordinary thing, that child health, mid [midwifery], um… family planning, drug and alcohol, women's health, domestic violence, all that stuff – it coalesces, and you use it. [late career diabetes educator, 18-4-11, p25]

[18] There are also subspecialisations for diabetes educators within specialist diabetes treatment clinics to some extent, for example in Type I, Type II, paediatric, adolescent, or gestational diabetes education.

She felt that a chronic conditions role needed to have breadth in order to address the full range of issues involved in helping people with chronic conditions, and it is significant that the breadth of the role was one of the things which enabled her passion for doing it. She appeared less constrained than some other participants in terms of what models or tools she might use (and described using stages of change, motivational interviewing, a depression and anxiety stress scale, 'being with' the other individual [a model prioritised in midwifery and palliative care] and "anything that comes along" as relevant [Elise, late career diabetes educator, 18-4-11, p25]. She also described her role as being one of working out where the person was at, and how she could help them to live with their condition in a way they wanted to live. With this as the defining goal, she was enabled to work with people in whatever way she felt might help.

The culture of diabetes educators is also potentially an enabling factor in how diabetes chronic conditions healthcare is done. One of the requirements before becoming a credentialed diabetes educator is to work 1400 hours (roughly one year fulltime) in a diabetes centre. This means formal and informal mentoring within the diabetes educator profession during that time, and a level of specialisation in a particular disease and acculturation within that which was not present for most other participants. Elise described valuing being in a workplace where she had a sense of a big picture goal and not doing it on her own:

> Elise: *That* can be sustained, even when there are backward steps. Provided, if the general move is forward, and there's *-enough* -force, and *enough* people going with you. If you do it on your own, you can only drag that stuff for *so* long. [late career diabetes educator, 18-4-11, p39]

Nevertheless, other participants' roles also facilitated chronic conditions healthcare, despite not having the specific focus of diabetes educators. I observed opportunistic chronic conditions checks facilitated by the breadth of primary care roles, for example:

- where a patient visited for an emergency stitching of a wound, and a GP or nurse recommended a cholesterol check),
- the building up of trust relationships within rural pharmacy enabling specific chronic conditions advice, and
- the heightened attention given to lifestyle advice from a paramedic.

Similar examples of chronic conditions healthcare were regularly undertaken from within broader (primary care and primary healthcare) roles. However such opportunities were generally dependent upon available time, a constraint within primary care roles in particular, which is further discussed below.

7.3.2 Role as a constraint to chronic conditions healthcare

In this study, eleven of the sixteen professions researched, when asked, found their professional roles constrained rather than facilitated capacity to do chronic conditions healthcare. An additional two professionals (physiotherapy and general practice) were ambivalent. These professions were clearly expected to do chronic conditions healthcare, but felt that expectations to limit services according to Medicare precepts sometimes impinged on their capacity to do chronic conditions healthcare. Sometimes this was a constraint to doing chronic conditions healthcare at all, and other times there were constraints on the ways or extent participants wanted. The more rural or remote the participant, the less likely they were to be particularly concerned about role boundaries (disciplinary purity) being maintained. A commonly expressed concern was that chronic conditions healthcare was increasing, with a concurrent sentiment of 'I don't care who does it, or how, so long as it gets done; and preferably done well'.

Overall, eighteen of the twenty-six participants felt that their role (or some aspect of their role, such as the requirement to do acute care as well) limited their capacity to do chronic conditions healthcare. In this, they echoed the literature:

> The first and crucial clinical move is to express the commitment to stay with the patient, to be there to do whatever can be done. It is an enormous defect of health-care organizations that professionals often cannot express this commitment because there are constant territorial disruptions over who stays how long and does what. (Frank 2004, p. 218)

Participants within the professions of practice nurse, community nurse, pharmacist, GP, dietician and paramedic were particularly clear about role constraints. Allied health participants appeared less concerned about their roles, in contrast with their clear concerns about the impact of funding on the availability of their services to patients. Those participants who were concerned about role constraints and wanted to do more in-depth chronic conditions healthcare and longer-term management saw a need for change, whilst others, enjoying the existing capacities of the role they were in, did not see it as part of their particular role.

Those who did not see ongoing chronic conditions management as part of their role viewed themselves as gatekeepers (expecting to refer to those who did), or as specialists engaged for a delineated period of time to assist with a specific issue more than general management. Such short-term 'in-depth' chronic conditions healthcare was described by and observed in the professions of physiotherapist, psychologist, OT, hospital RN and EN, oncology nurse, social worker, dietician, diabetes educator and medical specialist; and for health promotions programs

which had a particular chronic condition focus. Mike was particularly pragmatic about his view of the role of an OT in chronic conditions healthcare:

> Mike: I mean lots of our stuff, in all honesty we're the small player – we come in, we fix our bit. We're not the key player, and we're out again. And not a huge drama for us, type thing. [mid-career OT, 3-5-10 p27]

He considered his role as more of a specialist or consultant to help solve relatively short-term technical issues with activities of daily living; with long-term work like monitoring or self-management support better done by other health professionals, preferably those who had more on-going and regular contact with the clients.

Other participants were concerned that their skills were not being fully utilised, and that they were not able to be as effective as they wanted. This was partly because of other people's limiting pre-conceptions and designations of what their role might include (almost universally within practice nurse and community nurse participants, and also mentioned by a paramedic). Where role preconceptions constrained activity to particular types, or excluded particular interventions, participants felt distressed. Practice nurses who felt underutilised expressed this clearly: Nikki compared the kinds of patients she was allocated in two workplaces and hinted to one GP boss about things she could potentially do [Nikki 20-7-09 p2], whilst Sandra discussed the reactive nature of much chronic conditions care (rather than systematic and anticipatory care) [16-9-09 p1]. Sandra was particularly concerned that it was up to GPs to generate work for her:

> Sandra: It is *not* generated from the GP to do chronic disease management very well in this practice, except for one GP. […] They're the owner. And they know how the system works, and they know that there's money in the Medicare item numbers, for chronic disease management. [mid-career practice nurse/nurse practitioner, 16-9-09 p3]

She clarified by example:

> Sandra: So we've got a new doctor who's from [overseas], so he doesn't know the Medicare system. So I have to bide my time and build a relationship with him, that he sees me as a practice nurse who knows anything - you've got to prove yourself constantly to any new GP coming through, that what your skills are. Because they don't know what you can do.
>
> Anna: And if there are seven GPs here and one is a regular, so that's actually six GPs you are currently proving yourself to?
>
> Sandra: Yeah. Yeah. So if you haven't got a GP that is *interested* in chronic disease management, and *interested* in working with a practice nurse to help get the systems in place, then things just fall over. Because **as a practice nurse we don't have any clout with Medicare, they can't just come and see us. If they could come and see *me* and I could get an item number, I could do all that. I can *do* it, but I can't do it because Medicare won't let me.** [mid-career practice nurse/nurse practitioner, 16-9-09 p3, bold emphasis added]

Role specifications (occupational boundaries), in the form of GP-determined access to Medicare item numbers for rebates, were thus limiting Sandra's capacity to do chronic conditions healthcare, in the way that she wanted and to the extent that she wanted.

The separation between acute settings and community settings (and/or poor transitions between care settings) was specifically voiced by one participant, however should be noted as something that was mentioned as an ongoing frustration (serious concern) for most. For this reason, the following example is more detailed than most: in order to convey the level of concern of participants. Ange had worked in the UK, and drew contrasts between normal practice for primary care there and that of her various rural experience within Tasmania. She was particularly unimpressed by basic primary care arrangements within the Tasmanian context:

Ange: Well, primary care's just pretty non-existent here, as far as I'm concerned. I mean things that would be standard practice… […] just normal referral processes. There would be things like, we've been having falls education clinics and falls prevention clinics since the day I qualified ten years ago. Pulmonary rehab's been up and running since I qualified ten years ago. Obesity clinics, diabetes clinics… all these things have always been in place in the UK since I qualified, and yet you come over here and it's *just* being talked about.

Anna: Do you think it's population based, do you think it's a numbers reflection?

Ange: No. No, I think it's the way that the health system works. I mean that's obviously a huge difference, UK to here, and I find that really difficult to work in this one, because I'm trying to get my head around the politics of how it all works, state, federal, where is it, what have we got to do. Whereas the National Health Service is just… you know, that's how it is, and that's how it is wherever you go in England. The policy's made, that's what happens across England, unless you're in private.

Anna: […] I'm trying to get a sense of whether the systems here are backward…

Ange: [interrupting, clear and definite] Yes! […] I think they potentially are better in Launceston and Hobart, if you look at Launceston they've got a bigger community centre from a physio perspective, and they're just hoping for more staff. They were doing pulmonary rehab until they had to withdraw services because of lack of staffing. So those models *were* in place, it was just staffing. Whereas [in specified rural area] it's not even in place, I mean it's still a staffing issue but…

Anna: A staffing issue, a structural issue, you said resources before, did you mean staffing?

Ange: Yes. I also think it's something that's just coming into people's mindsets now. I just think Tasmania's just a bit backwards, and maybe Australia as well, which has really surprised me. [mid-career physiotherapist, 18-8-08 p2-3]

She felt there was considerably more standardisation in what was available across the UK as normal NHS policy, than appeared to be available in Tasmania; and also that the separation between acute (hospital based services) and chronic (community based services) was too definitive. When asked what it was like working with people with chronic conditions, she said:

> Ange: [P]rimary care and acute care were very much intertwined in the UK, so um, we had a lot more outpatient-based primary care services, provided within the hospital structure. So the respiratory physiotherapist's role would be both in- and out-patients. [mid-career physiotherapist, 18-8-08 p4]

She felt that there needed to be more capacity for continuity of allied health services across acute to community settings, and more capacity for specialisation within allied health services – that by renegotiating the boundaries of particular roles, better chronic conditions healthcare could be delivered. In the meantime, she found working with chronic conditions patients frustrating and sometimes even depressing:

> Ange: I don't think we're managing them particularly well. What we do well is that we, someone that comes in with an acute exacerbation of a chronic condition, we patch them up, we get them better, we send them out. And what I find frustrating is the fact that well, that's it, and then we just leave them to get on with it, until they have their next acute exacerbation… [mid-career physiotherapist, 18-8-08 p2-3]
>
> Anna: So when you say it's frustrating working with chronic conditions, how did you find it in the UK? How did you feel about working with chronic conditions there?
>
> Ange: [Pause] I didn't find it frustrating there, I guess cos there was a process that made sense, and it just... flowed through, and we were just part of that process, and you could see outcomes being achieved. Whereas here, I don't see that. All I see is yes, we've reached our goal of getting that patient home, but we haven't looked at the longer outcomes of what's happening with that patient. [mid-career physiotherapist, 18-8-08 p4]

Ange did, however, see potential to expand chronic conditions healthcare services in rural and regional areas, *without necessarily changing staffing numbers*. She wanted Tasmania to transition towards a UK style model, of using hospitals as a base for allied health but increasing continuity for patients by having them see the one physio across hospital ("acute") and community ("primary care"):

> Ange: [B]y integrating primary and acute, it's an area that we can look at expanding services on as well. For example, like I was saying, the ward that's we've just been working on is a medical ward, where you will have fallers, you will have respiratory, you will have neuro. So you need to be fairly generalised in all three of those areas. And I see the future as being able to split that ward almost into two, and having a neuro physio who's got a speciality in neurological rehabilitation - that could also have expertise in falls, and falls prevention, as one role. And then respiratory being the other role, with an in-patient and an out-patient role - getting pulmonary rehab up and running, increasing cardiac rehab that we already do, having a respiratory inpatient role as well as seeing general respiratory outpatients. [mid-career physiotherapist, 18-8-08 p4-5]

She felt that sub-specialisation of physiotherapists, whilst maintaining role scope across acute and community locations, increased both job satisfaction and productivity.

In some cases, roles themselves were not considered a constraint, but rather the constraint was the time limitations imposed on particular roles. This was expressed by GPs and a dietician in particular, and attributed to peer and middle/upper management expectations of service delivery. It appeared that broader societal as well as professional expectations of primary health professionals were that they deal with acute illnesses in a timely manner, and that structures were arranged to suit this. These structures inherently deprioritised and therefore disadvantaged chronic conditions healthcare. For one GP, this amounted to a pressure not to have too many chronic conditions patient bookings within one hour. Even the OT comfortable with 'being a small player' in the spectrum of chronic condition services noted the impact that chronic conditions clientele could have on the rest of his work:

> Mike: Our time frame is the main drama. And again, if we start doing more chronic disease stuff and that chews up more time, then those in-and-outs become more of a drama, because they chu-chu-chu-chu-chu [choofing noise]… slip back further. [mid-career OT, 3-5-10 p27]

Some research participants expressed concerns with disease-specific service provision rather than improving primary healthcare capacity as a whole (programs that targeted specific conditions, but left other patients without equivalent services). GPs were also conscious of how their broad primary care role impacted on their chronic conditions capacity: that they needed to prioritise acute over long-term conditions constantly.

> Tom: I realised very early on that I had to compromise my style of medicine. […] And if you're in the middle of winter, you've got forty people who need to see you in a day, cos they're actually ill today, and someone comes in with a complex emotional problem… Ok, sometimes you do just have to stop, and you get an hour behind. And that stresses me out, I hate getting behind. And sometimes you just have to avoid certain areas, because you can't do everything. [late career GP, 22-2-09i p16]

It is possible that where primary healthcare is at maximum capacity or understaffed, that prioritising of acute conditions has a greater impact on workforce capacity to deal with chronic conditions.

7.3.3 Role scope as situationally negotiated for chronic conditions healthcare

In this research, it appeared necessary for individual working scopes to be negotiated in almost every situation (irrespective of the professionals or professions involved). With team care arrangements for most chronic conditions involving multiple professions becoming the clinical norm (as expressed in clinical guidelines), many tasks can be undertaken by multiple professionals from different health disciplines. The physical location of care also determined some of the

nature of kinds of practice. Boundaries were thus individually negotiated around each patient's circumstances, and job descriptions or verbal 'contracts' needed to determine who did what.

One practice nurse described how she was in the process of clarifying areas of responsibility for herself and a visiting diabetes educator:

> Sandra: [S]he says 'when I come here [general practice consulting rooms], you've done all the stuff I normally do, and that doesn't happen in other practices […]. So what do you want me to do?' So now we've clarified our role - I say, 'ok, if they're coming to you, you know that they've already had *this* done, what *I* would like you to do is work on their blood sugar monitoring more, insulin technique, make sure they are rotating their [insulin injection] sites - and if you look at more at the medication side of things, can you fill in *that* role, because that is something that I'm not used to doing'. So we are working out where the role boundaries are. [mid-career practice nurse/nurse practitioner, 16-9-09 p23]

In this case, the diabetes educator could not assume the same work had been done by different practice nurses – she understood what the normal working parameters were for that profession, however to some extent needed to get to know each individual practice nurse and each general practice separately. Sandra, conversely, as a practice nurse with particular interests and skills in chronic conditions work, had taken the initiative to negotiate 'value-adding' from visiting health professionals beyond her existing service provision, rather than have visiting health professionals as simply a double-check on existing healthcare work.

Community nursing was another sector where the role content was clearly shifting. Whilst community nurses are still largely independent practitioners in the field (eg when managing chronic wounds), inter-relations with the rest of the health sector had changed during Kathleen's career:

> Kathleen: When I started in this job, we as nurses did a lot of case coordination type work. We'd pull in other services to provide care, we'd advocate on clients' behalf to get access to some of those services. And then, it's really changed, 'cos you've got all these other service providers who've got their own case coordinators. So we will refer to them, in a formal process, with a formal document, and we might get feedback if we're lucky. They'll go in and assess, they'll do their own assessment that won't be based on our assessment […]. And if you're a person living with a chronic long-term condition, you can end up dealing with lots of different service providers, and it gets terribly confusing for them. [mid-career community nurse, 11-6-09 p4]

Multiple assessments, and individual negotiation of role boundaries, highlight the partial fluidity within the health system, where more than one profession may undertake certain tasks. For example, diabetic reviews may be done by GPs, endocrinologists, practice nurses, nurse practitioners or diabetes educators. Each of these may have to do separate intake assessments, in

contexts where patient notes are not 'patient-held' or shared between sectors. In this (largely community based) research, leadership in negotiation of such tasks came from multiple professions, rather than limiting tasks by occupation or sub-specialty, as has been the case historically. Tasks were not necessarily specified by medical directives (as in hospitals) or by formalised hierarchies (such as a practice owner or manager). In Kathleen's example above, once the GP had relinquished the task of doing a diabetic review, there were still at least two health professionals who initially considered it their role. It takes awareness of task replication / redundancy as an issue, skilled communication, and (sometimes unpaid) time in communication and negotiation between health professionals, to avoid repetition of the same process by multiple healthcare professionals.

Different people within the same profession also clearly conceptualized their roles differently. GPs Tom and Caitlin specifically noted that they did not see it as part of their role to 'psychologize', and preferred to refer for ancillary help for psychological work (see above). However Heather considered that she did quite a lot of mental healthcare work. She noted that people could visit her year-round and bulk-bill (that is, attend for free), whereas mental health care plans only allowed for five or six (subsidized but not free) annual visits to a psychologist, with potentially expensive co-payments on top of the Medicare rebate. She considered five or six visits annually generally insufficient for any longstanding major chronic psychological condition, and suggested that monthly visits might be sufficient for status maintenance for conditions such as Autism Spectrum Disorders (ASD) or severe depression, but not adequate for additional support (eg during situational or life changes) or actual behaviour change. Where a patient of her's had a lifelong condition which she felt needed monthly monitoring or support, she was happy for such patients to see her as a GP (and cheaper option), thereby being able to save allocated psychological visits for specialist support during crises (exacerbations or relapses). She felt that she could do good on-going psychological work such as teaching and reinforcing stress management skills, whilst leaving specialist support (medication tweaking or complex psychological work) to 'experts'. However, she also stated that, in her experience, many GPs were neither inclined nor particularly well equipped to do regular psychological support work, and saw the lack of more frequent and better funded psychological support as a gap in the present healthcare system.

For allied health participants, there was also the possibility they needed to extend their roles in particular circumstances. Mike, an OT, described doing speech therapy for children in remote communities (as instructed by a city speech therapist), because he was the only allied health

practitioner in town. He also found that in a larger rural area, he might have to shift roles when other professionals were on leave:

> Mike: You accept that you have to cover a bit for someone, and you accept that, if Maureen's on holidays - Maureen's the physio - and if no-one's covering her, that you probably need to stretch your line a bit more, have a look at their walking, cos no-one's going to come and see them for three months. [occupational therapist, 3-5-10 p22]

This, to some extent, echoes the 'specialist generalist' call with rural health in general. However, it appears that a specialist-generalist approach may be more possible (and even expected) of employees in chronic conditions healthcare settings, than might occur in acute settings.

For participants, roles thus both constrained and facilitated chronic conditions healthcare. However, whether roles constrained or facilitated, participants discussed individually negotiating the scope of roles in almost every context. Present job titles and position descriptions did not always delineate firm boundaries, and thus required individual negotiation. While this is potentially an advantage (useful flexibility in who does what, 'backing up' of major functions, competency-based functions rather than professional closure around particular tasks); it does mean that every professional relationship involves situationally negotiated role boundaries, needing to be individually crafted and maintained. This (in-house and individual) exigency, to negotiate how each person functions within given roles, may contribute to inefficiencies in the system. Research participants juggled tensions between job descriptions (functionalist prescriptions and static behaviour expectations for given roles), role conflicts (where role definitions are constructed differently by different people), and role making (where roles are defined by those in them, in relation to their own expectations and those of others around them). Where explicit role negotiations did not take place, redundancies and doubling up were described.

7.4 Personal experience

Another kind of external factor influencing chronic conditions healthcare was participants' personal experiences: their own chronic conditions, their experiences of close family or significant others' chronic conditions, and their personal journeys and motivations to do chronic conditions healthcare. I call these 'external factors', and discuss them in this chapter, because people's personal experiences and motivations largely involve factors external to the healthcare system. Examining people's motivations to do chronic conditions healthcare also returns this chapter to a strengths focus: the reasons that people are choosing to do chronic conditions healthcare. Irrespective of policy or planning responses, the personal experience of participant clinicians did construct and constrain how they engage in chronic conditions healthcare.

7.4.1 Motivations to do chronic conditions healthcare

Participants described a variety of reasons when asked why they do chronic conditions healthcare, ranging from the relatively disinterested and pragmatic, through to an almost a 'calling'. Several of these reasons follow.

'Because it's there'

Fundamentally, some of these healthcare professionals did chronic conditions healthcare because it was part of their day job. Caitlin expressed this clearly:

> Caitlin: [laughs] Well, the simple answer is **because it's there**, really. It's um…You can't be a GP and *not* do it. [late career GP, 10-12-08 p2, bold emphasis added]

While many of the interviewees went on to elaborate additional reasons for doing chronic conditions healthcare, many of them started with this reality. For Mike, "it just comes with the job" [Mike, mid-career OT, 3-5-10 p27]. However, as with most interviewees, he had reasons for staying doing it once started:

> Mike: It suits me. Partly cos I like the longevity of the client relationship, I like to actually get to know my clients as people and all that sort of stuff. Yeah. That's probably it, I think. And um, I probably also like the fact that some of them are complex. They're an interesting, challenging type job, cos they're not straight forward. Some are, some aren't, but a lot of them tend to need a bit of thought. [OT, 3-5-10 p27]

Josephine was phlegmatic:

> Josephine: It's how it is, and you can't change that, so it's a matter of making the most of what is there, and working with that, working with those people. [late career hospital medical day unit, Director of Nursing (DoN), 25-9-08, p6]

Such acceptance appeared to facilitate doing daily chronic conditions healthcare.

Healthcare service need: making a difference

Brenda emphasized the healthcare service need to deal with people with chronic conditions. She stated that with aging populations, and increasing incidences of diabetes, obesity, heart disease and lung disease in the community, that it was imperative to deal with such clientele [Brenda, community nurse / DoN, 15-6-09 p7], or as Elise said, to "make a difference" [Elise, diabetes educator, 18-4-11, p24]. Most people were more interested in making a difference for individuals than for the system or population as a whole: "decent outcomes for the person" [Rob, OT, 3-5-10, p27], or "actually helping people" [Brenda, community nurse / DoN, 15-6-09 p5]. This has been described in the literature as 'compassion satisfaction' (Stamm 2002, cited Wendt, Tuckey & Prosser 2011, p. 2).

Rather than 'compassion fatigue', most participants appeared energized by their patients' accomplishment of small goals, such as the normalizing of good chronic condition self-management within daily life (compared to patients who 'allowed' their chronic conditions to become acute and require crisis management). This sense of achievement was often stated in low-key ways:

> Mike: I quite like the fact that you actually make a difference in people's life occasionally. You know, the therapeutic feel good type thing. [OT, 3-5-10, p36]

Elise added that, while variety within diabetes kept her interested, it wasn't the only hook:

> Elise: It's not like saving lives makes a difference, like if a surgeon takes out the appendix, 'oh look at that I'm a hero, I just saved your life, off you go now and be appreciative of me forever'. The joke is that you had a good session when you walk out of a GDM [gestational diabetes mellitus] group and you've said to the girls, 'you already knew all of that, I just put it into context'. And they go, '*yeah'*. Which means, 'I hooked it on your hooks, it's not frightening, it's not scary, you already knew it, you were already doing it'. *That's* the challenge. And that's the win - of not making diabetes management something that sits over there. It is '*you* were going to lose weight anyway, let's be honest; it's been on your calendar for the last ten years. You were *thinking* you ought to increase your physical fitness. You *know* you should go and get a pap smear, and blood pressure checked and your eyes checked every year. Now you've got a reason to do it'. So it's just *bringing* it in, and normalising it as much as you possibly can, so - 'I was doing that anyway, wasn't I'. [diabetes educator, 18-4-11, p24]

Brenda described the satisfaction of accomplishing small goals:

> Brenda: So you start that way, and once you've achieved that, then you go to the next step.
>
> Anna: It sounds like you get a lot of satisfaction out of those.
>
> Brenda: Mmm! Oh, it's fantastic. Yeah. It's really good. […]
>
> Anna: So what makes *you* feel good about doing that kind of work?
>
> Brenda: That I am actually helping people - to become more independent, and to be more confident about *managing* their chronic condition. [community nurse / DoN, 15-6-09 p5]

Martin, while passionate about specific kinds of chronic conditions healthcare, was presently "doing it for money, ironically" [community health nurse/midwife, 21-9-10 p25]. However he was also motivated by nursing where health promotion and broader community development type approaches were enabled, and where system change was possible:

> Martin: I guess it's learning new skills, being more capable, seeing for yourself how a better primary healthcare system can work. So once again I guess it comes back to that primary health care. And I guess a lot of the… what we're doing at the moment is a learning for ourselves, but also hopefully developing a system that's more efficient, more rational… just bloody basic common sense really. [late career community health nurse/midwife, 21-9-10 p27]

Making a difference to both systems and individuals, and at the same time creating opportunities for 'common sense' healthcare, were inherently satisfying to Martin.

Trying to improve the big picture, and/or sense of service

Another sense of satisfaction was achieved by trying to improve the big picture: taking public health actions as part of normal work. While this has been discussed to some extent in Chapter Six, 'working beyond the individual' was not only a tactic for doing chronic conditions healthcare, but also a motivator for some participants (Kathleen, Joanne, Tracy). For others, this big picture included a sense of service. Wendy considered her work at least in part as service to community, and mentioned service more than twenty times in her interview. When discussing how she had taken over an existing rural practice for relatively small financial return, she said:

> Wendy: I probably am the sort of person who would say 'well, I'll make this much and we'll make sure we live on it'. But also I feel I am providing a service. So I feel, many times, that I need to commit to that service. Things like [local nursing home] - by providing the physio service there - I'm very much committed to providing that. I get paid for that. Probably don't get paid the right rate, and I've never really negotiated that. Because **I also see that as a community service, and there's almost a voluntary component to that.** [mid-career private physio, 24-5-11 p9, bold emphasis added]

Elise also had a big picture motivation:

> Elise: So it's the people in the middle, that *have* the passion, and *have* the get up and go, and that can miss a lunch break to make a change, can think about 'if I spent a weekend and I went to that study day in my own time, I could do that, learn that, and bring that back here, and maybe that would get us closer to that goal' - because if that goal is well articulated, and we know the goal is really about *money*. But you can interpret that to say it's about people staying at work, it's about people staying engaged, it's about people staying with their families, it's about not costing the health care system, which means money ends up in the education system or the policing system or something else instead – that's what we all want. So you can interpret that in a meaningful way. **We believe that we can, those of us that stay in, I think, believe we can influence that** - even if it's only a bit at a time, we can get closer and closer to that goal. [diabetes educator, 18-4-11 p34, bold emphasis added]

She described an almost religious motivation for doing chronic conditions healthcare, despite not being of any practising religion but having Christian influences when growing up [Elise, 18-4-11 p36]. At one point during the observation period, she had what I noted in field-notes as a 'rant' about the proposed pulp mill project in northern Tasmania. She directly connected dioxin output with diabetes increase, and was passionate in her belief that the pulp mill should be stopped at least partly to avoid health impacts in that community. I asked whether her green or Christian beliefs were part of her motivation to work with people with chronic conditions:

> Elise: I'm sure that they are part of the same thing really, aren't they. […] Well, it's about, I think, just seeing yourself as a part of something beyond yourself. […] - a sense that… things went round. And that everyone had something to contribute. And that we all belonged, and had responsibility to other parts of that organism, which extends to an awareness of the environment - that what I do to the tree, then the tree can't support the next thing which can't support the next thing, which means I'm not supported. [diabetes educator, 18-4-11, p35-36]

For Elise, her family-of-origin Christian ethics and her environmentalism contributed to an ethos which motivated her both to pursue healthcare work as a young adult and then to maintain engagement longterm:

> Elise: I think I have something to contribute. I want to be part of that process, of making things better. [diabetes educator, 18-4-11, p34]

Intrinsic interest

Intrinsic interest within chronic conditions, and around chronic conditions healthcare, was an unexpected finding for me. Prior to fieldwork I had expected increasingly frequent presentations of particular conditions might lead to 'battle fatigue'. In my interviews, I generally found the opposite: rather than battle fatigue, more acute engagement with every individual in front of them; as separate, different people who might share a particular condition but very little else. I did find that, in order to avoid or manage 'battle fatigue', people worked part-time. Tracy was the youngest participant (29yo):

> Tracy: I've already decided that I don't want to work fulltime again.
>
> Anna: Ever again?
>
> Tracy: Maximum, point…, you know, four days a week.
>
> Anna: Yep. What about when the kids move out?
>
> Tracy: Nup. [early career dietician, 6-5-10 p31]

A more experienced allied health professional agreed:

> Wendy: I think I need time *away*, from my clinic, to actually sustain and keep me fresh and happy, and enjoying what I do. [mid-career private physio, 24-5-11 p13]

Participants generally felt that the pace and/or intensity of healthcare work lent itself to doing four days a week work (nevertheless sometimes doing fulltime hours over those four days). Some described preferring to have a long weekend or a day off midweek, in order to catch up on household and/or caring responsibilities, or non-healthcare work (eg family farm). Others changed jobs (eg took a locum role in order to have a change of scene, or shifted in and out of management roles), thus creating career trajectories of escalating and de-escalating chronic conditions involvement. By seeking respite or change from chronic conditions healthcare, people enabled subsequent re-engagement with chronic conditions healthcare, sometimes in a different way or at a different level.

Intrinsic interest within chronic conditions presented in two main ways: particular fascination with the people who lived with the conditions and with their 'stories', or particular fascination with 'the science' and particularities of a certain disease or diseases.

Intrinsic interest in *people* was a strong unifying thread within the research, in particular within those employed in primary healthcare. The process of becoming engaged in people's stories had become a highlight of healthcare work for most of the participants – and was an aspect of work apparently better enabled by working longitudinally with people with chronic conditions, than by working with people 'off the street' with acute conditions. Participants valued the capacity to do more in-depth work with people, and to engage more with their 'stories'. The first interviewee to make this clear was Heather, who talked about the evolving story of a patient with diabetes whom she had seen over many years:

> Heather: It's a *story*, and when you go through that with someone… - I hadn't actually thought about that, the story keeps on getting written. It's a story without end until *they* die, and I've seen a few people with chronic conditions die. And it's like... the notes, you write 'deceased' on the notes, tie them up in a bundle, and that story is... written. But it is, it's being part of a story, and it's actually very... I think rewarding. Which is interesting, because **many years ago, *I* wanted to do anaesthetics, or pathology, or emergency medicine, which you see someone and they *go*. [laughs] It's a *very*, short story. I didn't *want* to be involved in the long term, and it's surprised me that I'd like that part of it now.** [mid-career GP, 23-9-08 p14, bold emphasis added]

Other interviewees also enjoyed engaging with the 'stories' of their patients, and noted that this sometimes enabled clinical insights or assistance:

> Mike: I mean, almost everyone's an interesting person if you get to talk to 'em. Lots of the oldies around here have had really interesting lives, people that you see, quiet old Mrs Smith from down the street, and she'd run a one-woman *bullock* team, dragging logs out of the forest in the fifties. […] You'll think, oh god, that sounds terrible, but **the oral history part of the job these days, it's almost the bit that interests me *more* than the medical bit**. The medical bit, you kind of walk through the door and you know what you can and can't do – the oral history bit, the interesting people bit, is … kind of the *nice* bit. It's the dessert of it, […] You just, you meet some lovely people. [occupational therapist, 3-5-10 p17-19]
>
> Mike: And I think that even if you say, **half of that is just interesting, but it also allows you to do your job better**. If you actually do take that half an hour to have a cup of tea with someone, you actually do find out a lot of kind of useful information from our [OT] perspective – you know, you find out about their history, you find out a bit what they really do on a daily basis, you find out that they do really love their garden but they can't get down to do it and all that sort of stuff. And **sometimes you can't fix it, but sometimes you actually have, 'oh, I might be able to offer you something'**. [OT, 3-5-10 p37, bold emphasis added]

Elise agreed:

Elise [T]hese people are just the most extraordinary people. They do things with the worst possible resources, with a whole lot of crap and *idiot* people talking to them constantly, and yet they get on and do it and they make life for themselves anyway. [further examples]. It's that human spirit that keeps you hooked. [diabetes educator, 18-4-11, p7]

Enjoying the complexity

Initial intrinsic interest in specific diseases or conditions was rare, with only two of the twenty-six participants specifying particular conditions of interest. Jane thought it was more the breadth and complexity of chronic conditions in general which created interest:

Jane: I find the chronic diseases are so *complex,* that, while it is repetitive, in *some* aspects - like with diabetics you're making sure they are going to the optometrist and checking their feet and all the rest of it - but there still is a *variance* in there. There's always something *different* that would take you in a different *tangent* or a different... sort of like, to make them interesting. [mid-career practice nurse and child health nurse, 9-12-08 p8]

Mike agreed, enjoying both complexity and ambiguity:

Mike: You know, the answer might be a bit of psychological stuff, a bit of equipment stuff, a bit of care stuff, a bit of changing habits stuff. Rather than, 'I know I can give you this bit of equipment off the rack and that will resolve your issue.' You get a bit sick of those sorts of easy solution answers. Whereas the complex ones are interesting because there's not a straightforward answer. [occupational therapist, 3-5-10 p7]

Caitlin thought similarly:

Caitlin: So when you say how do I keep interested in giving the same advice: each patient is *really different*. And they're all so different from a psychological point of view. So there's the two aspects really, there's the physical and there's the psychological if you like, so you're always having to mould your advice or your approach according to the person's psyche as well, so determining that is part of the process.

Anna: And the entertainment?

Caitlin: [Laughs] Well, exactly, and so I guess if you take up the interest in people as individuals, then it's *never* the same. [older GP, 10-12-08 p6-7]

One healthcare professional that did have specific condition interests specialised in diabetes and depression, within a general practice role focusing on women's and children's health. Heather generally only saw males who had diabetes or depression, otherwise preferring to see women, and described being satisfied by diabetic work because it was methodical and systematic. Diabetes and depression work gave her pleasure, partly in "ticking off the boxes" (being comprehensive and meticulous), but also through attempting to improve (tweak) the different biological responses to medication and diet (particularly with motivated patients). As an outlier with specific interests, she nevertheless demonstrates that becoming knowledgeable and skilled in particular 'flagship'

chronic diseases influenced her broader practice style and interests. Her enjoyment was corroborated by Caitlin:

> Caitlin: I think I really more and more enjoy the intellectual *challenge* of it. I mean I always have enjoyed that. But… more so probably, as you get, you don't have to think so hard about what you are going to do, each person you see - then you can think about these more peripheral issues. [older GP, 10-12-08 p30]

Participants also noted what they perceived as the natural variety of work within rural jobs: variety by acuity, disease, geography and client. Mike summarized what he saw as assets of rural generalist positions:

> Mike: I really quite like the mix thing. I like being a generalist. And I like the fact that if one bit's not that exciting, then the next job will be something different, type thing. […] A few of them who are interesting and complex is good, all day would drive me *nuts*. And that's part of the reason that I work in these sorts of settings, is that you can do a little bit of everything. It just suits my temperament, I think. [occupational therapist, 3-5-10 p5]

Caitlin considered she would get bored if she saw the same person too frequently in her general practice, so preferred to book longer appointments and see people less frequently:

> Caitlin: I mean I would find it tedious to have to – that's what *I* actually get bored with, you said 'do I get bored with the saying the same things'; well, I actually get bored with seeing the same person every week. That's what *really* I don't like. [GP, 10-12-08 p33]

Lauren was in the position of training other health professionals on a regular basis, and described observing a sense of helplessness felt by many healthcare professionals feel when confronted by conditions where 'nothing can be done'. She had observed that when clinicians (particularly inexperienced ones) feel helpless, they often put emotional blocks between themselves and patients, where medical options were limited or exhausted and psycho-social needs were the primary focus of clinical work. She felt that healthcare professionals felt less helpless when they were trained in highly patient-centred care models: that by prioritising patient needs (including social and emotional as well as medical), there usually *was* 'something you could do to help'. She talked about trying to motivate clinicians to stay interested in patients for whom they 'could do little':

> Lauren: [Y]ou've got to find the motivation from some other sense of satisfaction in their job [than doing something which works]. And satisfaction, that they don't actually have to feel so helpless, in the face of this person's suffering. They can actually, maybe they can even bear to find out how much suffering's going on there. *If* they know there's something they can do - I think it's a sense of helplessness, that puts a block up. [medical specialist, 12-12-08 p6]

Brenda also reinforced the satisfaction of being able to help, even when that help was not medical:

> Brenda: I find it very satisfying, because a lot of people when they have got a chronic condition, they just don't know where to go. And if you've got some type of training and the tools to assist you to actually steer them in the right direction, it's very helpful. [community nurse / DoN, 15-6-09 p8]

Religious motivation

Other people had more explicit religious or spiritual motivations to do healthcare work, and chronic conditions healthcare in particular. Jane mentioned being a church pianist, and Sandra and Tracy explicitly credited their faith as fundamental to their lives:

> Sandra: Being a Christian gives some, gives me a foundation of who I am, and how I practice anywhere. So it probably *is* an essential part of who I am, and how I see things.[…] When I come to work though, often times I've been in the car coming to work, and I will be praying, saying 'please let my judgment be excellent, please let my skills be fantastic today'. […] And I pray that I am not judgmental, that, you know, you're kind to people - because having a chronic illness can make you feel like a bit of a whinger. […] So [pray to] have some patience. And be kind. And *listen* to them. [mid-career practice nurse/nurse practitioner, 21-9-10 VTI p18]

Lauren had previously been a practising Buddhist, and inducted into a particular mindfulness technique (tonglen[19]) which she found useful in work contexts:

> Lauren: [S]omething clicked in me, I suppose, that made it *easier* to walk into suffering. Do you know what I mean? And to still take care of myself in the middle of it. […] Yeah, I suppose it's mindfulness that makes it possible. […] I don't have the beliefs that I used to have, I don't have particularly any beliefs any more, which is very freeing. So I'm more able to work with the beliefs of the person in front of me. And that is really very helpful. […] I suppose my… my 'beliefs' I suppose, allow me to not take so it *seriously*, all this stuff that's happening. [late career medical specialist, 12-12-08 p32-33]

This was typical of most of the research participants: while their worldviews were not necessarily the immediate motivation for doing chronic conditions healthcare, such worldviews strongly coloured their predilections for particular kinds of work, and their particular ways of doing such it. It also seemed that people with a particular vocation towards client-focused chronic conditions healthcare chose to operate in that mode irrespective of their job title, and pursued positions where such skills were valued and utilised.

Rurality

Rurality, to some extent, appeared to function as a motivator in itself. Participants described getting satisfaction from things they attributed to their rural and regional locations:

[19] A Tibetan Buddhist practice involving breathing in the suffering of others, and breathing out relief of that suffering (Chodron 2007).

Josephine: I spose it's the relationship that you have with people and the family, to some extent. I mean, I visited the Royal Brisbane recently, for a day, and had a look at what their setup was like. And you just see all these swarms of people coming through. And I imagine the staff are trying to personalise it as best they can, but gee, it must be difficult. [late career hospital medical day unit, Director of Nursing (DoN), 25-9-08, p10-13]

Caitlin worked in a very stable population area, and found it deeply sustaining:

Caitlin: Well, I did sort of say about that it is very satisfying to do in a longitudinal, in a small community in a longitudinal way, didn't I, that's *really* … you know. I think.

Anna: That's what keeps you doing it?

Caitlin: *Yes*. Yes. *Much* more satisfying than sitting in a city practice and seeing people that you've hardly ever see before, and might not ever see again; and who just pop in because they want a referral to the specialist down the corner. [laughs] [late career GP, 10-12-08 p33-34]

Mike also appreciated the work-life balance he felt living in a rural area enabled. Unlike most of the participants, he worked fulltime, but rarely took work home:

Mike: So yeah, I don't take stuff home. Quite often work an extra half hour or hour a night, or work through my lunch hour or whatever, but that's not a drama, that's not expected, it's just my choice to do that. […] Being in Tassie, not too much travel time – I grew up in Sydney, and I spent an hour each way each day travelling, and accepted it – just thought it was normal. [Here] [i]t's like twenty odd minutes on my bike into work and things, which I quite like – and it's a lot less hectic ride, so that I like. Got a nice house and all that sort of stuff. […] I like it these days – quiet night, read my book, go to the pub! [laughs] So it's good, life, work type balance, type thing. [mid-career OT, 3-5-10 p35]

The quiet satisfaction some participants got from making a difference in rural and regional communities, appeared to enable their long-term continuity in particular roles.

Participants also described an increased level of independence and creativity as possible in rural and regional areas. Mike had worked in urban, remote and rural locations, and was presently enjoying the rural:

Mike: I think you've got a degree of autonomy more than you would have, professionally. Cos you're sort of a relatively small department, so you can do what you see is… not being slack, but you know, justifying a good result if you need to be slightly left of centre or something like that. Or someone really deserves a lot more extra time, there's no-one particularly looking over your shoulder - if you want to do that, that's fine. [OT, 3-5-10 p37]

Having a supportive partner was mentioned as another enabler of chronic conditions healthcare:

Joanne: I do have a supportive husband who is great to talk to. [health promotions worker, 2-7-09 p20]

The capacity to debrief, and to share other activities beyond the work contexts was important to personal sustainability in rural chronic conditions healthcare, corroborating earlier findings that a critical minimum of social needs are important to rural sustainability(Spinaze 2003, 2009a).

To summarize, it is clear that research participants had a range of motivations for doing chronic conditions healthcare. They presented reasons which can be viewed as on a continuum, from 'because it's there' (obligatory within primary care roles), through to demonstrated passion and pursuing of specific roles enabling a chronic conditions focus. Some found it inherently interesting, some enjoy the longitudinal relationships and stories, and others sought to 'be useful' or make a difference to patients. Helping to improve the overall big picture of chronic conditions was, for some people, as important as helping individuals; as was doing work which was congruent with existing worldviews. Sustained motivation was generally enabled by relationships with people (as discussed in Sections 3.3.2 and 6.3) and a sense of efficacy as a healthcare professional, even where efficacy was at the level of supportive listener as much as biomedical intervention.

7.4.2 Own chronic conditions

Participants also discussed their own chronic conditions, with approximately a third of participants having experienced chronic conditions of their own. At least two participants spontaneously brought up experiences of clinical depression. One noted that "how you feel in yourself" was a kind of barometer for her motivation to do chronic conditions healthcare, and vice versa:

> -------: If you're not feeling too flash yourself, it's a bit of a 'can't be bothered with other people's problems'. […] I've got a bit of history of depression. […] And I prefer not to take medication. And so work's been a blessing – cos I can usually function well enough to get up, get to work, and do things. It's been other things where you don't function so much.
>
> Anna: The outside of work – the [rural] property, self-maintenance, self-care?
>
> -------: Yeah. So work's actually been a blessing, it can be quite soothing. [de-identified participant F, p17]

Another noted that she had completely reassessed her life (including work) after an autoimmune disorder diagnosis:

> -------: I think that that's when I decided that I wasn't just going to be a slave to the job. That it wasn't making me happy. And I mean, my chronic condition, if you like, is *totally* manageable now, I mean I can't play sport anymore, but it doesn't … you know, people are worse off. But I think it's that defining time, and the direction I've taken since then, would, apart from changing my approach to my work, and what I want to do and how being a bit more *aware* - like it shifted my awareness of

> my day to day: how am I feeling when I'm at work. But it also made me *understand*, a little bit more, I think, what people have to go through when they are diagnosed. [de-identified participant E, p27-28]

This participant explained that the day I had been observing her work "I was probably *as* stressed as I get - afterwards I thought, 'well! she saw the total extreme'."

> -------: And at the end of that day I went, well, actually I told the owners, I said I'm not working like that anymore. […] I see no reason why I had to be put under the pump, like that, on a day that I know is one of the busiest days of the year, for [the business]. So now I will action that, and I will say, 'by the way, don't expect… that's *not* ok'. You know.
>
> Anna: Yes. And so, in some respects, your own chronic condition has really… become a driver, in a way, for expectation of appropriate management, so that you can manage your own condition?
>
> -------: Yeah, I just don't see why people should have to be put under pressure that's avoidable. Because number one, they don't perform as well. You are putting people under risk of mistakes, and missing things, and I just don't… I'm not going to engage in being part of that. And I've made a choice, I'm just not going to be part of that. […] And we find it a lot more satisfying, in life, to live that kind of life. So actually, I'm quite… it was a beneficial stage in my life. […] [I]n the context, you recognise that that significant event changed your life, much for the better. [de-identified participant E, p27-28]

Another had a different perspective, suggesting that her possible Asperger's diagnosis enabled methodical chronic conditions healthcare:

> -------: I *enjoy* diabetes, I think that it's part of, part of being on the spectrum, because...
>
> Anna: Being on the spectrum?
>
> -------: Being on the autistic spectrum. [laughs] Because [sing-song] you do your feet, you do your eyes, you do your this, you do your that, have you seen this person, have you had this checked, every few months there's boxes to tick. And then you can look at their blood sugars, because you get their blood sugars in, and you go, 'ok, this one's high, so what are we going to do. Shall we try this, let's just try this and see if we can get it... right'. [de-identified participant B, p8-9]

She had moved from having a general interest in preventative healthcare to having a specific interest in chronic conditions healthcare as a complex, intricate dance for both the patient and health professional; moving between medication management, lifestyle management (exercise and diet), stressors, genetic and environmental factors.

7.4.3 Significant other's chronic conditions

Approximately a third of participants had carer responsibilities for people with chronic conditions, as well as their professional healthcare work. Caring responsibilities were both full- and part-time, for residential and non-residential family (young and adult children, ageing

parents). Such responsibilities clearly affect people's availability for work (to varying degrees), and also attitudes to chronic conditions healthcare. One described increased empathy as a result of (a) a training exercise where she had to 'be a diabetic' for three days, and (b) her personal experience of living with someone with a mild chronic condition:

-------: I take my *hat* off to *any* family that has an insulin dependent diabetic child. It's *huge*. I mean, part of one of the courses that we did we had to be a diabetic for three days - I gave up after two, it was too hard! They *can't* give up. You know, my life was too stressful at that point, so I couldn't be the diabetic for day three. [But] I could go on strike. You [patients] can't do that, and that's part of some of the courses you do, you've got to experience it. It's important to do that sort of thing, and I can't quite imagine what it's like to be, to have arthritis and stuff like that.

But I know, I live with someone who's got a bit of osteo-arthritis; and that's enough - to be inconvenient at some points. And you sort of think well, far out, what would it be like to be totally… 'I can't hardly get out of bed some days and the drugs aren't working, you're running out of drugs, they've tried everything, nothing's working'. You know? [de-identified participant A, p15]

Another participant was a single parent carer for two children with special needs. However, rather than disenabling her from chronic conditions healthcare, this had actually enabled it. She described having an absence of support to do other things as crucial to keeping her in primary healthcare rather than specialist work, and developing interests in breastfeeding, depression and diabetes:

-------: It... it's also life circumstances, [discusses being a single parent]. And I think if I had that freedom, if [son] hadn't arrived, or I had a partner who was, let me do all those things, I probably would have done more, probably would have gone up to town and continued with the antenatal clinic, or done other things. But I haven't done that. Because my interests have been here, and then [first son] with the [chronic condition], and needing to do more here, and then [second son with different chronic conditions] coming along, and there's just all that stuff to do. And gradually over the years, you just think, no, that all, that stuff's just not possible. I just haven't got the time. [de-identified participant B, p15]

She described loving and being intensely engaged in her present largely chronic conditions healthcare, despite not having had an initial natural predilection for it.

One participant had a daughter with a serious and unstable mental health condition. She was in her middle fifties, but had determined ten years previously not to 'climb the career ladder' because of her daughter's intermittent but urgent needs:

-------: We've got aged parents. You know my mother died last year, but had, you know, a lengthy illness in the dying process. My father had bowel cancer. You know, we've got my mother-in-law who's well into her nineties, so you know my husband is her chief carer. I have a daughter with chronic [mental health condition]. Um, so you know it's gone from –

Anna: It's not easy.

-------: It's just gone from one to the other. You know, it's just the 'continue on' stuff. But […] [m]y career has always been very important to me, but not at the expense of my family. So my family would be…

Anna: One of those boundaries?

-------: Yeah, there's a real boundary around that. And a long time ago I decided that I wasn't going to, you know, go into the senior executive service, because I wouldn't be able to fit that in to my lifestyle, that my family's very… […] Oh, that was a choice probably consciously made when [daughter] got really ill, so probably fifteen years ago. [de-identified participant C, p15]

Another discussed how she was motivated to maintain a strong exercise regime (including gym attendance throughout pregnancy and early parenting whilst remaining at work), by her brother's experience of chronic conditions:

-------: I've never skipped it altogether. And that's partly because we've got depression in our family as well – I mentioned that my brother passed away – he actually had bipolar, which was misdiagnosed as depression. And he eventually took his life, thought to be on the wrong medication. So we've got strong depression lines in our family, and I just wanted to, I just need to make sure that I do that exercise each week so that I don't start trying to fight the black dog as I call it. [de-identified participant D, p18]

Participants thus had intense personal experiences of some of the realities of living with severe chronic conditions. These personal experiences both motivated and sometimes disenabled chronic conditions healthcare; increased and sometimes decreased available energy for work and patient needs. Such experiences were being taken into account within participants' own planning for healthcare workforce participation, as well as within how they do chronic conditions healthcare with their patients.

7.4.4 Chronic Conditions Healthcare does affect people personally

While personal experiences had impacts on the ways that participants did chronic conditions healthcare, chronic conditions healthcare itself also had impacts on the people doing it. Tracy discussed being "more aware of things":

Tracy: Like, on your days off, you'll be down the street and you'll see all these people walking around, and you can just look and think 'chronic condition, chronic condition, chronic condition'. [early career dietician, 6-5-10 p24]

Elise described using her skills in encouraging self-management within her ageing in-laws:

Elise: Not last Christmas but the one before, […] Papa [surname] and I were having a conversation, and I just started dropping hints, cos Mum's getting, just slightly a bit demented I think, at eighty-eight it's not surprising. And just, '**when will you *know* that it is time to get people into the house and start helping you, when will you *know* that Mum needs more care than you can provide,** have you thought whether you would go with Mum if she went into more assisted accommodation or whether you would stay in the unit? Have you had a conversation around it, have

> you *thought* about that?' Which is pretty confronting. I can get away with it because I'm not one of the kids, and then they can go and say 'that Elise, nah nah nah nah', but it actually *starts* things. […]
>
> So. *That's* my role, bit of a devil's advocate. Yes, just to *get* the conversation, get people starting to think. […] So that it's kind of an *expected* thing - not 'oh well, it's a sign that you're failing and you're not coping' - so 'when will you know', that's the language that we use in the diabetes centre all the time. [late career diabetes educator, 18-4-11 p44, bold emphasis added]

Elise was helping her father-in-law to create an expectation of decline *as part of a normal pathway* - along with an awareness of signs to look for and to use as triggers for pre-determined and mutually agreed engagement of higher level services - rather than decline as a surprise, a crisis or a personal failure. She agreed that in this personal context, it was very useful to have the diabetes educator training, and thus an ease with getting people to self-assess when situations were changing, and when and what to do something about it.

Mike described a 'lack of effect' on his personal lifestyle, however noted that chronic conditions healthcare pushed him to live in the moment:

> Mike: [M]y theory with the health stuff is you either worry about it or you make a conscious decision not to worry about it – and **I think I'm the person who works in health who just thinks, 'nah, bugger it, don't go to doctors and all that sort of stuff, cos you sort of see the limited success they have'**, and all that sort of stuff. No. That has probably pushed me in the opposite sort of direction, **get along and enjoy life, don't worry too much about health issues type thing**. […] [R]ather than the 'be careful and protective of yourself, look after yourself' - my diet and all that's fairly atrocious. […] I don't think it affects me that much, type thing, tell the truth. [mid-career OT, 3-5-10 p37-38]

Martin felt differently, that it did push him to live a healthier lifestyle:

> Martin: [Y]ou realise the benefit of trying to live a fairly healthy lifestyle. Minimising the adverse lifestyles that are going to cause… so eating well, exercising, keeping your brain active, participating, you know, building social capital, and all the benefits that flow from that – you know, keeping community bonded, I guess, in some way, just a little way, contributing to that. […] I guess you've just got to avoid things that may precipitate mortality. [community nurse / midwife, 21-9-10 p20-21]

Tracy described how working with people with chronic conditions affected both her professional practice and her personal habits (for herself and her family):

> Tracy: But how has it affected my life? I think it's made me more aware of what I do or don't want to do in my own life. Making sure we all are eating healthy. […] Um… what else? Weight bearing exercise I'm more, awarer [sic] of that now. Also aware of calcium excretion as well, like making sure my body is alkaline, to try and prevent that calcium excretion from the bones. So making sure I do avoid soft-drinks and salt, and having plenty of fruit and vegies, that sort of thing. Um… diabetes – I suppose I try and spread my carbs out throughout the day, not get overweight, stay active. [early career dietician, 6-5-10 p25-27]

Tracy was thus actively pursuing a lifestyle constructed to minimize the risks of certain chronic conditions.

7.5 Summary

In Chapter Seven I examined external factors (funding, role and personal experiences) which impact on doing chronic conditions healthcare. Funding patterns, professional roles and cultures, and personal experiences and motivations all contributed to the construction of participants' chronic conditions practice patterns. While some environmental factors enabled and made possible good chronic conditions healthcare, others constrained or problematized. Roles were generally perceived as both constraints and facilitators of chronic conditions healthcare, however funding logic, inflexibility and structural *sequelae* were seen only as constraints. Participants' personal experiences also clearly determined the type and style of present work, and were thus analysed as environmental (sociological) influence on chronic conditions healthcare. For chronic conditions healthcare; funding, roles and personal experience shape the style and type of work people do.

PART THREE: DISCUSSING AND CONCLUDING THE RESEARCH

8 Discussion: Dimensions of Chronic Conditions Healthcare

8.1 Introduction

Part Three of this thesis returns to the research aims discussed in the Introduction. So far, the thesis has addressed the initial aim of making chronic conditions healthcare more visible ('what is it like to do chronic conditions healthcare?'). In doing so, it also examined the research sub-questions:

> What are the issues for such health professionals in doing such work?
>
> What are the strengths of such health professionals?
>
> What are the strengths of chronic conditions healthcare itself?

I now move towards the second part of the primary research question: 'what does it mean to do chronic conditions healthcare?'. Considering what it means to do chronic conditions healthcare necessitates "another trawl of the texts (which by now includes the chapters in this thesis as well as the transcriptions and field-notes)" (FitzGerald 1995, p. 263). Part Three thus functions as an analytic counterpoint to the previously presented findings in Part Two.

In this final section, I discuss particular dimensions of chronic conditions healthcare (Chapter Eight), and some implications of the research findings (Chapter Nine). In the final chapter (Chapter Ten), I revisit the key parts of my argument, and lay out the contributions of this thesis. In doing so, I answer the primary research question ('what is it like, and what does it mean, to do chronic conditions healthcare?'), whilst demonstrating that the experience of chronic conditions healthcare is a common yet largely un-discussed phenomenon.

As discussed in Part Two, the principal findings of the research are that:

- chronic conditions healthcare is a distinct entity, being created by practitioners in response to a changing practice environment.

- chronic conditions healthcare has particular characteristics, including commonalities other types of healthcare work.
- chronic conditions healthcare requires specific tactics, which the Australian healthcare system presently struggles to accommodate.

Chapter Eight presents some overarching dimensions of chronic conditions healthcare, drawn from the findings (healthcare professional perspectives) and the literature. These dimensions are integral aspects of chronic conditions, and therefore of chronic conditions healthcare:

- ambiguity
- complexity
- contingency, and
- temporality.

While each of these dimensions can be seen as typical of chronic conditions (actual diseases, conditions and illnesses), they are also characteristic of chronic conditions healthcare (tactics, techniques, clinical guidelines). Definitions of each emerge in the sections below, with participant examples and literature "provid[ing] resonances, side-lines, points of contrast, related insights and questions" (Mol 2008, p. 98). However these dimensions rarely present singly, but rather blend into each other - much as symptom management blends into behavioural strategies, and symptom lists become diagnostic criteria. I therefore present these dimensions in pairs, in order to illuminate some relationships between them. I do not consider this presentation exhaustive, but rather illustrative, of some ways in which some aspects of chronic conditions healthcare can be understood. I do this rather than address aspects individually and thereby isolate each in ways which might not be insightful or useful (have real world relevance).

8.2 Ambiguity and complexity

In chronic conditions, wellness blends into un-wellness and single conditions into multiple. Chronic conditions are therefore inherently ambiguous, and the tactics required to manage chronic conditions equally so. Chronic conditions healthcare involves preventive activities, which blend into chronic conditions specific interventions[20], which move into acute exacerbation or emergency responses: the ambiguity of moving subtly between generalist and specialist skills. Correspondingly, where ambiguity is present, healthcare work is inherently more complex: there are multiple options for both clinician and patient to consider, and both patient and clinician will

[20] NB secondary and tertiary prevention of chronic conditions are particularly important, however "*our ability to prevent disease by reducing the levels of risk factors is far weaker than our ability to prevent complications in existing disease*, as in the case of anticoagulation to prevent stroke in patients with heart failure and atrial fibrillation, or pneumococcal vaccination after splenectomy"(Weingarten & Matalon 2010, p. 138, emphasis added).

decide. The lack of acuity allows time to gather further information (even have the patient visit further clinicians such as allied health or medical consultants), and to then consider multiple intervention options. No single path will unambiguously provide a solution to all issues. With both patient and clinician considering option, the balance of power also shifts continuously, creating further ambiguities and complexities. Whilst a diagnosis may be clear (such as medically defined diabetes or obesity), prognosis and treatment options are often multiple (which medications? how many? how much exercise? how much diet change? who will drive the process?). Where there is no singular clear clinical solution, and no singular clear 'leader' in decision-making, complexity and ambiguity reign.

Increased complexity and ambiguity also increase uncertainty. Montgomery asserts that "the status of knowledge in clinical medicine may be uncertain, but knowledge in practice is firm" (Montgomery 2006, p. 201). However, in (non-emergency) chronic conditions contexts, this research suggests otherwise; that is, that even as the status of knowledge in chronic conditions sciences is often uncertain, equally knowledge of practice in chronic conditions healthcare is also uncertain. Pragmatic choices may predominate, as despite clinician awareness of clinical guidelines and 'best practice', the patient in front of a clinician may accept one drug but not three. The clinician is put in the position of knowing that there are multiple options with competing assets and deficits (ambiguous and complex choices), of which different patients will need different levels of awareness. In chronic conditions healthcare, clinicians must simultaneously 'perform certainty' *and uncertainty* (see (Montgomery 2006, p. 199). She or he must convince a patient over a long duration of time that certain interventions are necessary, at the same time as there is no certainty that such actions will result in desired outcomes. The health professional must explain potential as well as current symptoms of a disease or condition, and lay out various possible natural progressions; involving the patient in repeated, longitudinal decision-making based on individual cost-benefit analyses.

This is in contrast to other healthcare contexts (such as surgery, birthing, or paramedic work), where the short timeframe requires a short-term performance of certainty (and elimination of uncertainty if at all possible). Limited or no time is available during emergencies, to express uncertainty where uncertainty exists, or to explain the complexities of various competing risks. The health professional's role in such situations is to reassure patients and onlookers that this particular health professional is in charge, has a sense of what is happening, and knows what to do next. For health professionals trained largely in such contexts, decisiveness and 'taking control' become the *modus operandi* and hallmark of the professional. Where present, ambiguity

must be down-played (minimised or temporarily eliminated), and decision-making for the patient sometimes limited to (hopefully informed) consent. When healthcare professionals are used to operating in this framework, 'changing gear' to accommodate longer timeframes, and sharing rather than 'taking control', are necessary but difficult. A chronic conditions patient has expertise in understanding how different treatments affect them; and so health professionals need enact a slower, more measured performance of *both* certainty and uncertainty. In such situations, health professionals doing 'chronic conditions management' may feel ambiguous about the benefits of their present work; uncertain about their abilities to achieve 'successful outcomes' given the lack of (their own or other people's) successful earlier interventions. A lack of clarity (ambiguity) around what a successful outcome is, as well as how to achieve it, increases the complexity. Health professionals may feel ambiguous about work where solutions are complex rather than clear, and even feel uncertain about their capacity to work with people with chronic conditions at all.

In such situations, Montgomery proposes that "[i]ntellectual knowledge… is always trumped by the ethics of practice" (Montgomery 2006, p. 203), where the ethics of practice demand reassurance alongside provision of the clinician's genuine sense of the situation. The ethics of practice demand reassurance that, whether the future (and the patient) be good or bad, the clinician will support and advise through any outcome. However, with chronic conditions, the locus of who is expected to be in charge of decision-making has shifted; and I suggest that the locus of the ethics of practice thus shifts as well. May notes that

> … the more that we have examined the practices of healthcare technologies and organizations, the more we have observed the collapsing boundaries between patient, carer, worker and professional. (May, C 2009, p. 5).

The patient may be reassuring the clinician that s/he will take certain actions - can be counted upon to execute particular steps in the treatment plan - and to some extent thus establishes an ethics of practice for themselves as a patient. Such ethics of practice, rather than the more generalizable clinical ethics of practice, will necessarily be individual, specific, and limited as a social contract – an implicit contract between two individuals (as much as between 'clinicians' and 'patients'). While this also occurs in acute conditions (for example, an expectation that a patient will take antibiotics appropriately), the longitude and frequency of this kind of social contract within chronic conditions professional-patient interactions increases the pressure on such arrangements. Longitudinal contexts increase both the ambiguity and the complexity of patient-professional relationships.

8.3 Temporality and ambiguity

Longitudinal contexts are inherent in chronic conditions, and this extended temporality, in partnership with ambiguity, determine much of the nature of chronic conditions healthcare. Temporality and ambiguity both play an important role in defining and identifying chronic conditions. Chronic conditions last a long time, *and* are uncertain, disputable, changeable, and perplexing. Determining when a chronic condition begins is highly ambiguous, and often only discernible in retrospect: when does chronic conditions healthcare with an individual patient begin? Ambiguity within temporality is thus a determinant of the nature of chronic conditions healthcare; in that the health professional as well as the patient must struggle with uncertain diagnoses, disputable treatments, changeable responses to treatments and perplexing (and equally intriguing) individual variation.

As discussed in Chapter Five, health professionals observed and interviewed in this research had individual, sometimes multiple and generally implicit definitions of chronic conditions healthcare. The uncertain prognosis of many chronic conditions, even with the "terra firma of physical diagnosis" (Atkins et al. 2013, p. 6), creates ambiguous ground for clinicians as they attempt to assist patients with their chronic condition/s journey. A recent paper (Atkins et al. 2013) looked at the experience of medically unexplained physical symptoms (MUPS), a category generally considered to be at the more difficult end of healthcare work, and suggests physicians and patients alike "suffer in silence and isolation when they encounter … diagnostic uncertainty" (Atkins et al. 2013, p. 3).

One of the key ambiguities with defining chronic conditions healthcare is thus determining when it is, and when it isn't; that is, where chronic conditions (and therefore chronic conditions healthcare) begin. Diabetes, asthma, depression and many other chronic conditions have subtle beginnings, imperceptible to both patient and health professional, and diagnosis is largely retrospective, signalling the need for immediate, interventionist healthcare. The determination of when and where professional chronic conditions healthcare begins is thus subtle, but also crucial as Heather noted:

> Heather: I think a third of people when they present have already got eye problems, from the diabetes. So, when I see people who haven't had those things done... yeah... I mean, my wanting to...
>
> Anna: Your alarm bells go off?
>
> Heather: Yeah. You want... to get them... Let's do this properly. [mid-career GP, VTIi 23-9-08 p9]

More than one participant in this research suggested that chronic conditions begin in the womb. Some thus saw their roles in pregnancy and infant/mother support as preventative chronic conditions healthcare: preventative healthcare with a chronic conditions focus. For some participants, diagnosis was already 'too late', in particular to achieve a reversal or 'cure'. While only a few participants were directly involved in health promotion, one GP wished she could 'eliminate three-quarters of what's in the supermarket' and 'get more people breastfeeding' [Caitlin, late career GP, 10-12-08 p8-9]. Statements like this highlight ambiguities inherent in chronic conditions healthcare – that while health professionals must largely be concerned with the 'here and now' of clinical needs, they wish that either they personally (or other parts of the health system) had more capacity to intervene, at other stages of chronic conditions trajectories.

Some wanted their work to span the breadth of potential chronic conditions healthcare, from population level preventative work, through to preventative work with individuals, through to clinical support for individuals post diagnosis. Others preferred their work to remain in one or two of these zones, but wanted other zones better dealt with (more highly prioritized in funding and resources), particularly where preventative work was concerned. Chronic conditions healthcare thus rests on a paradox: that while concerned with long-term conditions of *ill*-health, the healthcare professional wishing to improve chronic conditions status must be active during *health*. Comprehensive (rather than reactive) chronic conditions healthcare thus targets both the 'healthy' and the unwell, those at risk as much as those diagnosed.

The possibility of disease existing in the absence of symptoms is another aspect of ambiguity inherent in chronic conditions healthcare. Not only is it difficult to determine when a chronic condition is beginning; but in some cases, patients and health professionals may disagree regarding the status (existence or otherwise, seriousness) of a patient's chronic condition. For example, health professionals sometimes consider people 'ill' once they have a chronic condition diagnosis. Patients, on the other hand, may not consider themselves ill at all, even where a diagnosis (recurrent depression) or biomedical markers (such as HbA1C in diabetes) suggest, or even 'determine', otherwise.

Such ambiguity creates tensions, in that healthcare professionals may feel the need for interventions, which patients do not feel or see a need for. The healthcare professional may feel obliged to convince the patient of their ill health, despite their present asymptomatic experience and status. A definition of chronic conditions healthcare thus rests on the presence of *risk factors* for a chronic condition, as much as actual confirmed (medically diagnosed) presence of a chronic

condition: "the irreversible presence, accumulation, or *latency* of disease states or impairments" (Lubkin & Larsen 2006, p. 6), emphasis added.

In addition, certain locations of healthcare work are inherently ambiguous for chronic conditions healthcare. Ambiguous chronic conditions healthcare locations in this research included:

(1) a medical day unit,
(2) a palliative care support unit, and
(3) an ambulance.

In these locations, which are neither part of a hospital nor wholly 'in the community', patients may not be in immediate danger of dying, however not be inherently well. Equally, working in acute settings (high intervention, short-term care locations) did not preclude clinicians from categorizing their work as chronic conditions healthcare – for example, despite being attached to a hospital (a relatively acute healthcare setting), one of the clinicians involved considered "ninety percent" of her unit's work to be chronic conditions related [Josephine, late career hospital medical day unit, Director of Nursing (DoN), 25-9-08, p8]. The ambiguity of chronic conditions healthcare is thus not necessarily clarified by location.

Equally, whilst participants from the first two of the three above locations conceptualised chronic conditions healthcare as 'work where they would be seeing a patient for an extended period' (often weeks, months or years), the paramedic also considered a large proportion of his work as chronic conditions driven, despite seeing patients only relatively briefly and largely as once-off encounters. He appeared to conceptualise many crises as 'acute exacerbations of existing chronic conditions', and therefore substantively chronic conditions healthcare (even though it was less common for him to have longitudinal relationships with patients).

Whilst the extended temporality of chronic conditions is unquestionable, one cannot presume that chronic conditions healthcare necessarily has the same extended timeframe. For example, in emergency and acute care work a health professional may see a patient only once (have no durable relationship), but still consider themselves to be doing chronic conditions healthcare (in response to acute exacerbations, in doing an opportunistic 'brief intervention'). Equally, healthcare professionals doing 'locums' (in-fill for clinicians' holidays or sick leave) cannot be presumed not to be doing chronic conditions healthcare, simply because a health professional does not have a longitudinal relationship with the patient. The presumed extended temporality of chronic conditions *healthcare* (although not the actual status of whether the work is chronic conditions related or not) is problematized by the inherent diversity within chronic conditions

healthcare requirements: both acute and longterm care will be required, usually from multiple providers within a healthcare system.

While participant experiences of doing locum work were not actively canvassed in this research, one GP described locum positions (or once-off consultations with patients who normally consulted other doctors in the practice) an opportunity to review existing care. She felt such consultations were a crucial opportunity to review for gaps, and (occasionally rather than typically) to suggest alternatives; for example, where a patient was not responding to existing treatment and/or expressed dissatisfaction. Such reviews of care are crucial to longitudinal chronic conditions healthcare, opportunities for renewal or refreshment of 'tired' tactics, which have potential to make overall care more beneficial to a patient; particularly in more contained rural or remote populations where patients may see the same practitioner for a number of months or years.

Neither specific locations, nor extended temporality, are thus exclusive markers for chronic conditions healthcare. Definitions of chronic conditions healthcare therefore need to account for clinicians doing chronic conditions healthcare where single encounters between a clinician and a patient are involved; further contributing to the inherent ambiguity of chronic conditions healthcare.

A definition of chronic conditions healthcare thus rests largely on the known (or inferred, pre-diagnosis) presence of a chronic condition, and/or risk factors for one or more chronic conditions. Does this make chronic conditions healthcare merely a new term for (or re-branding of) primary healthcare? As a result of this research I suggest not, in that this resarch ascertains the presence of a particular sector of work within primary healthcare. Terms such as 'chronic conditions healthcare', 'long-term conditions work' or even 'long-term conditions healthcare' might reduce ambiguity, by giving a more specific focus to one (rather large) part of primary healthcare – thus engendering more understanding of what it is that primary healthcare professionals primarily do. Whilst the extended temporality of chronic conditions healthcare cannot be eliminated, some of the ambiguities may be able to be. If the primary care, primary healthcare and tertiary healthcare sectors are more and more about work generated by chronic conditions, then naming that (presently un-titled but substantial) portion of such work could assist in better targeting research, training, and funding - towards chronic conditions healthcare as a significant part of all health sectors.

8.4 Complexity and contingency

While many chronic conditions are complex in themselves, most patients have more than one diagnosis. This results in poly-pharmacy (a common clinical picture already discussed in Section 2.3.1), inherently complex in itself; as each drug intervention has separate actions, side effects, and interaction profiles with other drugs. The use of multiple medications to address multiple conditions in chronic conditions healthcare can be an exquisitely sensitive therapeutic tango: each action and reaction contingent upon each other. Chronic conditions healthcare thus becomes a process of interfacing with interplays of chronic disease(s), multiple treatment(s), and both patient and professionals' social conditionings: interlocked complexity and contingency.

Where individualisation of treatment occurs, complexity of clinicians' understandings of a particular disorder is increased. As stated by a number of participants, this in itself may become a motivating factor; that is to say, 'increased interest may come with increased complexity'. Equally however, where complexity is increased, the contingent nature of conditions and treatments is more prominent. The more complex a patient's disorders, the more likely they are to need multiple interventions. Multiple interventions come with multiple interactions: each intervention has side-effects (good or bad), in particular with more than one pharmaceutical intervention. Complexity and contingency are therefore intertwined in chronic conditions healthcare.

The other crucial aspect of contingency in chronic conditions healthcare is the dependence (increased contingency) of the healthcare professional upon the patient's healthcare work. In chronic conditions healthcare, the patient needs to put in the work before the clinician can be deemed effective. The clinician's healthcare work is (to some extent) judged on the basis of the quality, quantity or absence of the patient's healthcare work, creating a kind of contingency nexus. In almost any other kind of healthcare, the patient is more dependent on the clinician than *vice versa*. A trauma patient needs immediate intervention or in-house care, a midwifery patient and family need shepherding through preparation for birth and early mothering, and a palliative care patient and family need preparation for death and the early processes of grieving. In contrast, in most chronic conditions healthcare, once stabilised the patient may be independent of the clinician for most of the patient trajectory (possibly even entirely - independent other than for re-scripting). The patient is generally an ambulatory, non-institutionalised, largely self-managing entity, and visits the health professional as an intermittent resource: whether at 'best practice' levels, or (as some participants reported) at a tolerable sufficiency; that is, turning up for visits but 'not doing much else' in between. A chronic conditions consultation is thus something to be fitted in to the rest of real life, rather than a necessity (a non-optional, non-deferrable visit

occasioned by illness which interrupts and/or threatens to curtail 'real life'). If, as discussed by Maree, the clinician's sense of self-efficacy is often dependent on apparent professional efficacy (positive and measureable patient response to clinical intervention), then chronic conditions health professionals are considerably more dependent on patients' work than acute trauma health professionals.

The multiple locations and actors within that chronic conditions healthcare may also add complexity. In the normal course of a chronic conditions patient journey, long-term conditions work may alternate between:

(1) "the home … [as] a suburb of the healthcare system" (May, C 2009, p. 4) (self-care, partner/familial care, neighbourly care),

(2) the community (community health professionals including GP, nurses and allied health; patient may be ambulatory or housebound), and

(3) institutional sectors (hospital or institutional care).

Where the location of chronic conditions healthcare is multiple and various, and power is spread across the boundaries of the actors involved (patient, carer, health professional, consultant), there is increased ambiguity. Treatment thus becomes contingent on who makes the healthcare decisions, and when and where decisions are made. Treatment options are also contingent on the location of potential interventions, and the ambiguity is increased: which actors make which decisions, in which locations and when? Contingency as well as complexity thus becomes inherent in chronic conditions healthcare.

8.5 Contingency and temporality

Contingency and temporality are also interwoven. Agich notes that:

> …[w]hen someone says they do not have time for something, they deny that thing its relative importance or value. When they make time for something, they focus attention on it, and so thereby value that thing (Agich 1995, p. 141).

By making time for a particular symptom or aspects of a chronic condition, clinicians imply that that aspect is more important at present; and that other aspects of the chronic illness experience may be contingent upon managing that aspect. Temporality has been much considered within chronic illness literature, as the most obvious distinguishing feature. Roth, in particular, did early work looking at 'career timetables' for patients and physicians (similar in concept to illness trajectories), noting that no-one

> … is ever completely the helpless pawn of career contingencies. His own actions will have some effect – little in some career lines, great in others – on how nearly he can stay on schedule (Roth 1963, p. 116).

This underplays the *contingent* nature of chronic conditions. All conditions and treatments (acute or chronic) involve change, temporary or long-term. However, as discussed previously (see Section 2.3), when a person develops a long-term condition, to some extent it is their own activity (or inactivity) which will largely determine when it will be diagnosed, what kinds of treatment will be considered, and who will implement such treatment. Unlike in short-term condition contexts, the efficacy of chronic conditions healthcare is contingent on the work of the patient as much as the work of the healthcare professional. In asking 'who makes the diagnosis, who treats, who is the expert' (see Section 5.2.3), diabetes educator Elise emphasizes the shift in focus in terms of who implements changes. The more acute a condition, the *less* likely it is that the person with the condition will be doing the actual implementation of health-improving activities. The more long-term a condition, the *more* likely it is that the responsibility for monitoring, trialling treatments, monitoring changes, tweaking pharmaceutical and lifestyle responses, devolves to the 'patient'. The term 'patient' becomes almost redundant in some cases, for example where a patient actually changes their own drug dosages or frequencies, and then notifies the prescriber retrospectively. The administrative power remains with the healthcare professional, but the power to change the actual practice of any treatment resides with the patient.

While no patient is wholly in control of their own trajectory, it thus appears that for patients with chronic conditions their actions or inactions may be considered (correctly or otherwise according to individual circumstance) to shape the course of biological outcomes to a greater extent than in traumatic injury or life-threatening diseases with short prognoses. While long-term conditions can still be life-threatening, clinician expectations of the longterm patient may be generally higher than what they would expect of an acute patient. Acute patients are generally expected simply to be compliant with an immediate treatment option, whereas long-term patients are often expected to make lifestyle changes *and* take multiple medications (often with unpleasant interactions and/or side effects, which may in themselves require management, eg weight gain, sleep disturbance, gastrointestinal effects). I do not imply it is always simple for acute patients to be compliant; but rather to highlight a relative lack of expectation (from health professionals and the healthcare system) of energy and input on the part of short-term healthcare clientele. Where patients have been 'brought up' (had their only previous clinical contact) in acute healthcare, they equally are unprepared for a different kind of patient role, and, as previously argued, must "adjust their accustomed disposition" in order to take a more active role (Badcott 2005).

In an acute situation, a patient may hope for a quick fix, such as (lifesaving or pain relieving) surgery or medication. However in the case of long-term conditions, 'lifestyle changes' may include losing weight, changing diet, or give up smoking; all of which require major life reorientation, and for some people a rejection of their normal social and cultural milieu. Conversely, whilst clinicians may expect a lot of chronic conditions patients, such patients may have considerably lower expectations of clinicians than if they were in an acute situation. A chronic conditions patient is less likely to expect that the 'visit to the doc/nurse/physio' will fix absolutely everything (much as s/he may hope, consciously or implicitly, that the next medication trial and error process will 'sort it all out'). While healthcare professionals may aspire to 'effective care' (hope of positive outcomes or situational change), the experimental nature and lack of immediate outcomes for many chronic condition management strategies shifts the consultation emphasis in terms of both contingency and temporality, as well as the locus of agency.

'What clinicians do' in chronic conditions healthcare has clearly evolved into a specialised set of techniques and tactics, honed and brought into play for chronic condition situations. However, unlike in surgery, where the immediate assessor of the success or otherwise of an intervention is the surgeon her/himself, in chronic conditions the immediate assessor of effectiveness is the patient, who has time to consider whether present management is 'helping much'. Each treatment (evidence based or experimental) must be tried and assessed *by the patient as much as by the clinician,* for individual effectiveness and tolerance of side effects over a long period of time, and adjusted and re-trialled over time as the clinical indicators change. This shift in power also creates an emphasis on *how* people engage with patients, alongside what they actually do 'for' or 'to' patients. In a chronic conditions consultation, the emphasis may be as much on the ways or manner in which healthcare professionals relate to the patient, in each consultation, and over longitudinal relationships – rather than, or as well as, any actual or potential effectiveness of care. The question of 'what' clinicians should do (in the absence or reduction of expectation of success) has equal importance with 'how' clinicians interact, with the person at the centre of the consultation: the person with one or more chronic conditions.

The extended temporality and increased contingency inherent in chronic conditions thus shift the balance of power and equally the expectation of activity, from the clinician or healthcare system to the patient. This is a fundamental shift in power, away from clinicians and from healthcare systems themselves, and perhaps the central issue which dominates clinical as well as patient experience of chronic conditions healthcare. The clinician toolkit becomes as much about having a dynamic range of practical but also rhetorical skills, in order to introduce possibilities of

behavioural shifts to a patient, for contemplation and discussion. Potentially such clinical attributes could be considered attitudes; however this word suggests measurable psychological parameters which it is not possible to assess within a sociological context. Rather I suggest that clinicians evolve their own tactics and technique parameters (which interface with evidence-based guidelines and rhetorical skillsets, but may not be wholly determined by them), as part of a toolkit of clinical options.

8.6 Summary

Chronic conditions healthcare, like chronic conditions themselves, involves particular kinds of temporality, ambiguity, complexity and contingency. Engendered by the ambiguous, contingent, complex and temporal dimensions of chronic conditions, chronic conditions healthcare is thus similar to other kinds of healthcare work (rehabilitation, midwifery, where the focus is on patient-determination and patient-activation of interventions. From the perspective of the healthcare professional, the longitudinal context increases both ambiguity and complexity; which in turn heightens contingency. The presence of these four integral dimensions shifts the balance of power (centre of action), from clinician to patient.

9 Implications

9.1 Introduction

Chapter Five concluded with the observation that chronic conditions healthcare is either invisible, or where not invisible, not much reflected upon. This creates an evidence base for this chapter (Chapter Nine), in which I argue that it would be better if chronic conditions healthcare was brought 'out of the closet', made both more visible and more considered.

This research confirms that chronic conditions healthcare is in transition: in Australia as documented by this research and by (Dennis et al. 2007; Martin & Peterson 2008; Dobrow 2009; Jeon et al. 2010; Cheffins et al. 2012), and internationally (May, C et al. 2004; May, C 2006; Johnson & Chang 2008; May, C, Montori & Mair 2009; Mol 2009; Larsen 2013a). Some of the research participants and research facilitators were change managers within their clinical teams (recognized or informal), and explicitly described in negative terms what they considered out-dated styles of practice (apparent or believed present, in their own practice, or in other practice locations or sectors). For participants, Australian chronic conditions healthcare appeared to have less in common with healthcare work where the locus of control is task-, clinician- or healthcare system- dominated (eg emergency, surgical, and some aspects of paramedic work). Rehabilitation, palliative care, midwifery, primary healthcare, community-controlled indigenous health, and even to some extent rural and remote healthcare, were discussed by participants as influential on their current practice styles in general, and on their chronic conditions modus operandi in particular.

However, this perception of an attitudinal shift does not appear to be confined to participants. The literature implicitly indicates that chronic conditions healthcare is recognised as a separate set of skills, which to some extent rest on acquired techniques of engaging patients. Part of the change was perceived by participants as moving from 'old style' healthcare, where patients were expected to be compliant with hospital routines and traditional 'sick role' constraints; to 'more current' (implied: 'improved') practice, where even patients in hospital may be given considerably more responsibility (for example, being expected to shower themselves rather than have a bed-bath; to feed themselves without assistance). However, where knowledge of chronic conditions healthcare was an implicit rather than explicit understanding, such work was only implicitly allocated mental, physical and emotional resources by participants. Where chronic conditions healthcare was invisible, people were less likely to be interested in it, and to devote effort to it:

their perceptions of chronic conditions healthcare affected their engagement. Where they had a clear understanding of its centrality within their work, they allocated mental and physical resources (including undertaking specific trainings they felt could assist), and directly tackled apparent tasks and strategizing around chronic conditions healthcare. However, where participants were reliant on disease-specific models and smaller specific competencies, their perception of their own efficacy in chronic conditions related work appeared less positive, and their approaches largely task-oriented without the opportunity for 'bigger picture' chronic conditions engagement.

Professional attitudes to both in-patient and community-based patients with long-term conditions vary, as do expectations of patient involvement and agency in their treatment regimens (Charmaz 1991; Varcoe, Rodney & McCormick 2003; Annandale, Elston & Prior 2005; Dennis et al. 2007; Taylor & Bury 2007; Wilson, Kendal & Brooks 2007; Zuger 2008; Karnieli-Miller & Eisikovits 2009; Lindsay & Vrijoef 2009; Pilnick, Hindmarsh & Gill 2009; Atkins 2010; Lehnbom & Brien 2010; Thompson 2010; Yen et al. 2011; Isaacson et al. 2012). While not a comparative study of acute and chronic conditions healthcare, this research provides evidence that attitudes and approaches to working with patients with chronic conditions can be qualitatively different to work in other healthcare contexts. While some healthcare professionals maintain more static ranges of expectation of patient self-determination across a range of patient conditions (from chronic to acute), others subtly adjust their expectations for individuals by age range, socio-economic status, personality and also by condition. This research demonstrates that participants consider chronic conditions healthcare to be qualitatively different to other kinds of work they previously or currently participate in - at the very least in their expectations of patients, and at the most in terms of specialised tactics they consider appropriate to employ in chronic conditions contexts. Chronic conditions healthcare appears different to other kinds of healthcare work; and the kinds of tactics and foci of approaches discussed in Chapters Five and Six are evidence for this. However, without an explicit field of engagement, healthcare professionals and systems are meandering. This chapter outlines some areas in which, with direct research and policy attention, chronic conditions healthcare could improve.

9.2 Shifts in agency mean constant negotiation (and more flexibility) required

Perhaps the most striking factor is the extent to which chronic conditions patients may shift within their lifetimes between independence and dependency *and vice versa*, with consequent shifts

in agency and autonomy. Healthcare professionals need to constantly adjust their expectations of the same patient, and may be at more risk of getting their understanding of the patient's independence level wrong than where more traditional versions of the sick role were enacted by both clinician and patient. When healthcare professionals assess levels of dependence or autonomy incorrectly, clashes may occur, and with increasing numbers of chronic conditions patients, such clashes may be more frequent. The more well or healthy a patient, the greater their agency and the less 'fit' to more acute and paternalistic styles of healthcare. However, the more labile a chronic conditions trajectory, the less predictable their level of autonomy or dependence. This has implications for how clinicians and healthcare systems function.

Similar issues have occurred in maternity care, where 'reflexive consumers' are impacting on both "the 'macro' level of health policy, [and] the 'micro' level of doctor-patient interactions" in ways "which, some have argued, have the potential to disrupt the dominance of medicine" (Zadoroznyj 2001, p. 118), see also (Thorne & Robinson 1988; Cook & Easthope 1996; Lupton 1997; Walker, R 2003; Groenewegen 2006; Rowe & Calnan 2006; Bondi 2009; Karnieli-Miller & Eisikovits 2009; Zadoroznyj 2009; Klein 2013). Palliative care, rehabilitation and oncology may provide parallels of other clinical work where success is redefined (away from 'successful treatment = health', towards 'successful treatment = improved quality of life'). Midwifery may also provide clues (given its focus on 'well women' rather than unwell), as many people with chronic conditions may define themselves as 'well' (according to their own definition of wellness) much of the time. Any determination of chronic conditions healthcare standards needs to reframe the definitions of clinical 'success', towards optimising rather than ensuring health, and towards monitoring as a gateway to opportunistic improvement ('tweaking') as well as an end in itself.

Chronic conditions healthcare thus also destabilizes medical dominance in a number of ways:

(1) Patients may be expert in their own condition, its likely trajectories, and best ways of management.
(2) Some healthcare professionals may be 'more expert' than other healthcare professionals: such as diabetes educators compared to GPs for some things, and GPs compared to diabetes educators for others.
(3) Medical professionals may have competing expertises: for example GPs (as generalists) and medical specialists (as organ system specific experts) may offer contradictory advice.

However *no-one presently knows who is more expert, in which circumstances.* Expertise levels shift situationally, within the patient themselves (according to how unwell they are, and how familiar

they are with this particular kind of unwellness), between different healthcare professionals, and between different medical professionals. The patient may be most expert in managing day to day, the diabetes educator most expert in managing insulin usage fluctuations during an infection, and the doctor (such as a GP, endocrinologist or cardiologist) may be most expert in which drugs, how many, and in what combination might best prevent or reduce particular disease *sequelae*. All these different experts need to negotiate with each other. However, in the end, the patient will decide who to listen to - whether a 'best practice' expert, or a neighbour who 'found this on Google'.

Chronic conditions trajectories mean that independence and autonomy of patients varies, and that trust within the clinician-patient relationship is conditional. Chronic conditions healthcare needs better recognition of the importance of maintaining autonomous, independent patient agency; and services which support rather than disable this.

9.3 Individualist versus preventative (population focused) clinical encounters

Chronic conditions healthcare both manages existing conditions, and aims to prevent future ones. However, present Australian models of chronic conditions healthcare and funding prioritise individual experiences (and clinic attendance) over population measures. Patients are largely attending general practice or other primary health care services when they are symptomatic, rather than in an effort to prevent such symptoms. However, just as there are calls to address palliative care from a health-promotion framework (Kellehear 2005), where clinical services "empower patients and their families by taking an early intervention approach [including] add[ing] education functions to those of treatment, palliation and support" (p17), chronic conditions healthcare needs to prioritise preventative as well as symptomatic and curative treatment.

However, talking about preventative healthcare (primary, secondary or tertiary) does not necessarily sit comfortably within symptom-specific consultations. Mazza concluded that "a disconnect exists between patient perceptions of prevention in general practice and government expectations of this sector at a time when general practice is being asked to increase its focus and effectiveness in this field" (Mazza et al. 2011). Weingarten and Matalon argue that preventive medicine "cannot be shown to be more effective than curative or supportive medicine", and that "large amounts of general practice staff time" should not, therefore, be devoted to it (Weingarten & Matalon 2010, p. 138); noting also that the

> … traditional healing role of the GP requires a cooperative patient-centred approach, whereas systematic preventive medicine is driven by rigid pre-set protocols and is intrinsically paternalistic. Trying to merge the two approaches is detrimental to the doctor-patient relationship (Weingarten & Matalon 2010, p. 138).

A patient-centred approach, whilst laudable in its attempt to prioritise patient priorities, may result in focusing on discernible symptoms, rather than preventing less easily perceived changes in risk factors. This research cannot assess the relative merits of responsiveness over comprehensiveness (symptomatic management over prevention) in consultations, but rather notes that chronic conditions healthcare will always need to actively manage the tensions between the two. Both patient-centred and broader public health / health promotion strategies can enable individualist and preventative healthcare. However, whether all can always take place to the extent necessary to cope with chronic conditions prevalence, within the same clinical context or consultation, remains to be seen. The responsibility and weighting of individual clinician (and health profession discipline) roles to the various preventative (health promotion / public health), curative and/or symptom management approaches needs to be carefully planned.

At present, this research indicates that individual consultation lengths determine capacity for preventative as well as symptom-focused responses to some extent, particularly where Medicare requires GPs to act as gatekeepers and/or the principal primary health care provider. All three GPs interviewed mentioned the difficulties of balancing acute care and hourly throughput, with patients who were complex and needed more time to sort through multiple issues, and/or preventative approaches with patients who were not symptomatic but at high risk for chronic conditions diagnose/s. Lifestyle approaches (such as weight management and/or dietary changes) may work best before lifestyle diseases are actually diagnosable, eg preventing a shift from 'pre—diabetic' to Type II diabetes. Evidence provided in this thesis suggests that, with GPs and hospital clinicians focused on "patient throughput" (Kirby, SE et al. 2012), preventative healthcare and assisting patients to self-manage and self-prevent chronic conditions can fall by the wayside, being left to specific health promotion programs undertaken by other healthcare professionals; and potentially adding another delay for referral to such programs (many of which cannot be accessed or made available in rural or remote areas). Some of the more patient-centred yet time consuming tasks of chronic conditions healthcare described in this research are building self-efficacy, 'being with' the individual (including sharing the grief of diminished physical capacity), and nurturing people's fledging attempts to change their health (illness) trajectory/s. As discussed by Kirby et al (2012), one barrier to access for chronic conditions self-management is an undersupply of GPs trained and familiar with self-management programs; who might therefore refer if not actually undertake such work themselves. This research concurs that

"clinician support for patient uptake of CDSM [or any other type of more time-consuming chronic conditions healthcare] can still be neglected in an overworked general practice environment"(Kirby, SE et al. 2012). It thus supports calls for more resources in the community sector as a whole, for more funding to preventative healthcare within the community sector, and for more flexibility within the chronic conditions pathways (ability to refer for preventative work 'pre-diagnosis').

9.4 Different / more flexible funding, training and accreditation models required

Funding of healthcare is complex, and the specific solutions to problems identified in this research are beyond the scope of this thesis. However, participants were unanimous in their dissatisfaction with present funding arrangements for chronic conditions healthcare, with opinions I would categorise as 'mildly irritated' to 'completely un-impressed'. In particular, participants suggested that the longer consultations necessary to some chronic conditions healthcare are not presently facilitated (made easy) nor appropriately remunerated within present Medicare arrangements. Walters et al's research into chronic conditions self-management support suggested that "[d]ifficulties that led to early withdrawal were competing demands, insufficient time availability, phone calls having lower priority than face-to-face interactions and changing employment" (Walters, Courtney-Pratt, et al. 2012). This research suggests that similar issues face chronic conditions healthcare in general. Part of the problem is the narrow gateway, of referral through GPs that is required for all subsidized chronic conditions healthcare. In addition, health professionals need to continuously negotiate funding models, professional roles, and their geographic location (regional, rural or remote), alongside their own personal lifestyle choices, in order to make chronic conditions healthcare happen. Such negotiations may be limiting healthcare professional engagement with chronic conditions healthcare, as well as system efficiency.

While the present healthcare system is not chronic conditions focused, the healthcare system of the future will need to be. Evidence provided in this thesis suggests that examination is required, of whether the right numbers and the right mix of professions are being recruited for work in a chronic conditions-focused healthcare system. In particular, doing training for chronic conditions healthcare cannot be left up to individual interest (for example, through postgraduate study or short course certification after a number of years in practice). Chronic conditions healthcare training needs to be a fundamental part of all undergraduate health curricula (where it is not already). Staffing ratios (numbers of clinicians per patient), professional mixes (numbers and

types of different healthcare professionals per patient) and training patterns (expertise in chronic conditions healthcare skills as part of basic healthcare competencies) will need to accommodate chronic conditions healthcare as a higher priority.

Equally, it is important that every clinician consider social determinants of health for each patient, and the potential ramifications of those social determinants of health on each intervention. The setting in which the patient exists: their literacy, familial support, friendship circles, and access to resources, determines their chronic conditions outcomes as much as their healthcare. Activation of a chronic conditions patient (Kirby, SE et al. 2013), into a self-motivated self-manager, needs occur within their context (their social and environmental conditions). Chronic conditions healthcare solutions need to be place-specific, contextualised to the particularities of the local workforce, local clientele, and levels of local access to services. Planning realistically for the actual (rather than the desired) contexts in which the bulk of the patient's healthcare will take place; that is, the home setting and influences surrounding the home, will assist in determining realistic strategies. Lifestyle interventions in particular ignore social conditions of the patient at their peril. Addressing these involve a kind of attitudinal shift which needs to be inculcated during undergraduate training, during degrees presently focused upon the biomedical, "individualist orientation of the clinical encounter" (Braunack-Mayer 2011). Approaches appropriate to rural, regional and remote healthcare may give clues to tactics for urban centres. Metropolitan healthcare can learn from rural healthcare in the same way that rural healthcare is expected to learn from urban models.

It is possible that multidisciplinary competency based accreditation and funding models might provide a partial solution; that if someone is qualified and accredited to do a diabetic review, and has a provider number which indicates this, then the same rate of funding could apply irrespective of profession. According to the Productivity Commission, "there is already a degree of cross-skilling in some remote area therapy services, such as between occupational therapists and physiotherapists" (Productivity Commission of Australia 2005, p. 220). Carmel's study of intensive care concurs, noting that "[d]ifferences between medicine and nursing are exaggerated in clinical practice, for example there are many similarities between what nurses and doctors actually do" (Carmel 2006, p. 2079). This research extends that remote and intensive care evidence into rural and regional primary healthcare as a whole, into allied health as well as into different nursing and medical occupations. Participants' plea - that 'we don't care who [which profession] does it, so long as they do it properly'- is a call to (multidisciplinary) arms. The

evidence in this thesis supports an almost decade old call from the Productivity Commission, who state:

> … it is very important that a 'whole-of-workforce' perspective is brought to bear. […] While medical practitioners are integral to the provision of quality care in rural and remote areas, some participants suggested that nursing and allied health have often been the 'poor cousin' in policy deliberations…. Excessive compartmentalisation is likely to hinder further evolution in scopes of practice and the development of multidisciplinary care (Productivity Commission of Australia 2005, p. 241).

Equally, continued siloing between professions is likely to hinder evolution in chronic conditions healthcare.

9.5 Individual factors may affect who it is that undertakes chronic conditions healthcare

It is possible that doing chronic conditions healthcare marks out particular kinds of individual clinicians. This research is an initial examination to identify and understand the people who are doing chronic conditions healthcare, and the ways in which they do it. Given such evidence, it is possible that the converse is true: that 'who those people are' seminally affects 'who does such work'. Psychological profiling (similar to rural 'temperament' or 'trait' studies (Eley, Young & Przybeck 2009) could be of relevance; however equally of interest are the social conditions and social groupings which construct how clinicians evolve into chronic conditions healthcare praxis. This thesis is a preliminary sociological profile of whom it is, that might become interested in chronic conditions healthcare.

Another individual factor, a clinician's basic health and wellbeing status, was also clearly crucial to participants' capacity to engage in chronic conditions healthcare. Potentially, programs which can assist clinicians to stay well and healthy might contribute to increased chronic conditions healthcare capacity. The actual health and wellbeing status of clinicians in Tasmania is unclear (other than through the Healthy@Work data discussed in Section 3.2, which covers Tasmanian state service employees and therefore not GPs, pharmacists, or allied health professionals in private practice). With approximately one-third of participants having chronic conditions, as well as risk factors for chronic conditions such as being sedentary or overweight, the health and wellbeing of chronic conditions healthcare workers themselves needs further research. It would be useful to know more about the rates of chronic conditions occurrence, and chronic conditions risk factors in clinicians; in order to enable healthier working cultures. I was deeply concerned during all-day observations by the limited number of participants who took formal lunchbreaks, or indeed ate or took lunchbreaks at all. Given that some of these health professionals already

have chronic conditions, and that some medications for chronic conditions are digestion dependent, I found it worrying that it appeared habitual to skip or substantively delay meals (which were often then eaten whilst doing computer-based desk work). A sharp contrast was drawn by one participant, who not only took a ten minute lunch break but then did a twenty-minute walk 'around the block'. She specified on interview that she did this in order to be seen by her patients as a good example of prioritising her own wellbeing whilst at work, as well as simply to benefit from food and exercise during a long office day. A culture which prioritises a daily mid-work meal as well as 'getting through the list', and some movement as well as being sedentary, must be hoped to be more sustainable.

While the healthcare system cannot plan personal experiences into clinical training or lives, policy makers can at least be aware that, with ageing workforces, clinicians are likely to:

(a) have increasing personal carer responsibilities once in a particular age bracket; and

(b) bring understandings from such experiences into their clinical work.

Personal understandings may take the form of increased knowledge or awareness of particular conditions. However personal experience may also bring

(a) a need to escape from 'third shifts' (personal illness work, see Seear 2009) into 'first shifts' (paid work) or 'second shifts' (unpaid carer work, see Hochschild & Machung 2003 [1989]);

(b) a wish to avoid similar contexts at work as are being experienced at home (have a change of scene if not a break); or

(c) alternatively, a wish to engage in similar contexts as to home (increased motivation to work with people in similar situations).

While clinician responses to personal experiences are as individual as their experiences, reflexive employers and managers can stay aware of what is going on in their employees' personal lives. In this way, employees and employers can together formulate solutions which both take advantage of personal expertise and best support clinicians to keep enjoying work (thriving not surviving, see Wendt, Tuckey & Prosser 2011).

9.6 Extension of Wagner model

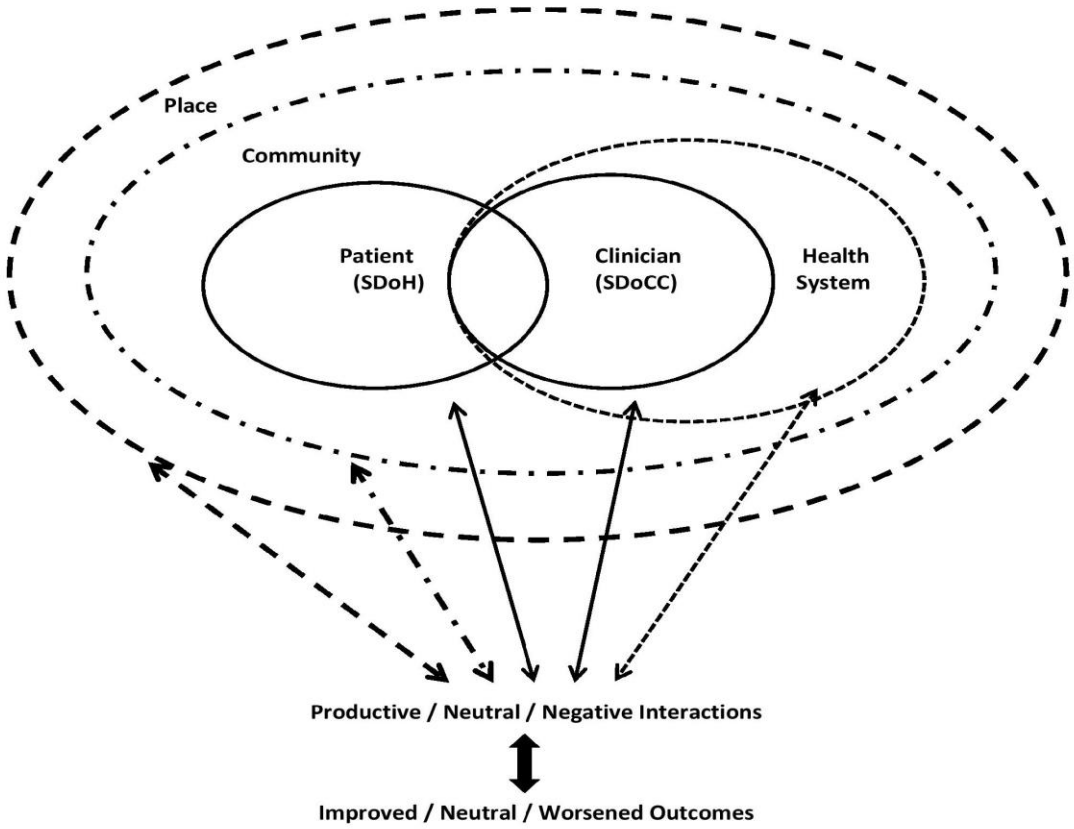
Notably, individual clinicians are absent from Wagner's Chronic Care Model. This research supports the model's formulation, that six elements are crucial to long-term conditions management. However I propose a more equal focus upon the individual patient and clinician elements, giving clinicians and patients equal weighting to 'Health System' and 'Community', and also adding a geographic element ('Place'), as a determinant of what is possible and available to all

healthcare (in this case, Chronic Care) constituents (Patient, Community, Clinician and Health System). My research demonstrates that:

(1) clinicians themselves (not only decision support tools, clinical information systems, and system design) have a crucial role.

(2) patients and their social and environmental contexts are equally crucial.

The version of the Wagner Chronic Care Model below takes this into account.



SDoH = Social Determinants of Health

SDoCC = Social Determinants of Clinical Care

Figure 2: Re-work of the Wagner Chronic Care Model

As with the original Wagner Chronic Conditions Model, 'Health System' includes Self-Management Support, Delivery System Design, Decision Support, Clinical Information Systems; and 'Community' includes Resources and Policies.

The circle of the (chronic conditions) patient necessarily includes that patient's illness status, illness history, illness trajectory stage, life history, life trajectory stage, age, gender, race, socio-economic status (past and present), social obligations (eg work, caring responsibilities for elders,

children or other dependents) and geographic (rural, remote or urban) location – the patient's present status is (at least partly) socially determined. In other words, the social determinants of health (SDoH) apply equally to patient chronic conditions experience.

Equally, the clinician's circle includes all of the above: an individual clinician's career status (present occupation and role), career trajectory, and also their personal life trajectory, life stage, age, gender race, socio-economic status (past and present), social obligations, and geographic location *determine the kind of care they have capacity to provide to the patient*. I describe this as the *'social determinants of clinical care'* (SDoCC): the factors which construct individual clinicians, teams, and healthcare systems' provision of chronic conditions healthcare. For this reason, the circles representing patient, clinician and health system are all within the circles representing community and geographic (place) contexts.

While the original figure (see Figure 1, Section 2.4.2) shows a 'Prepared Proactive Practice Team', it appears to neglect the fact that any team is made up of multiple individual clinicians, with different experiences, status (professional and personal), career and life trajectories, and at different stages of such trajectories. Such differences are to some extent culturally determined, but shape the kinds of individuals and therefore also the dynamics and constitution of teams. The personal and social milieus of patients are also neglected, other than the loose grouping 'community' shown at the top (with neither patient nor clinician inside it). This version of the model (see Figure 2 below) addresses these gaps.

I have also eliminated the 'effective self-management' heading, as my research indicates that self-management (in the formal sense) is only one part of multi-pronged 'effective management' of chronic conditions; and needs be facilitated by patients, clinicians and health systems. I consider self-management one potential outcome within the multiple outcomes likely; and thus include it (without listing it) within 'improved / neutral / worsened outcomes'. Note also that all arrows go in both directions: positive and negative feedback impacts both ways, equally for patients, clinicians, health systems and communities.

'Improved Outcomes', while a laudable goal, is not representative of normal chronic conditions illness experience. The reality for most chronic conditions patients and clinicians is that they will experience moments of improvement, times of no change, moments of crises and times of decline (rapid or slow); all of which may alternate. This version of the Wagner Model takes this into account.

It is also important to note that 'Improved Outcomes' according to one measure may mean poorer (or more expensive) outcomes in other contexts. For example, reducing hospital admissions may mean (indeed, may inherently *require*) increased usage of community based healthcare services. Saving money in the acute sector of the healthcare system may require increasing money into the non-acute chronic conditions healthcare sector (prevention, monitoring and community-based care services).

9.7 Summary

Chapter Nine has explored some implications of the research findings. In particular, it looked at

- shifts in agency (for patients and therefore for clinicians),
- the difficulties of balancing individualist clinical encounters with population-level approaches,
- participant concerns with funding, training and accreditation models, and
- the impact of individual experiences on who it is that does chronic conditions healthcare.

Finally, I presented a version of the Wagner Chronic Conditions Model which accommodates the research findings. This version of the Wagner Model shifts the focus to include the patient and the clinician as central parts of the model. It also highlights the effects of social determinants on clinical care as well as on patient health; presenting 'social determinants of clinical care' as a new concept important to understanding chronic conditions healthcare.

10 Conclusion

In contemporary Australia, people with chronic conditions require different ways of engagement, by both healthcare professionals and systems. This thesis has charted the terrain encompassing the individual experience of healthcare professionals doing chronic conditions healthcare, and the larger societal shifts which influence that lived experience. Current chronic conditions healthcare praxis comes from the intersections of multiple worlds. By this I mean that the worlds of healthcare systems, policy directions, and formal training intersect with cultural influences and personal influences, and patient load profile; to create chronic conditions healthcare. Profession, job description, race, gender, socio-economic, career trajectories, life experience, carer responsibilities, and personal illness or health status: all affect the doing of chronic conditions healthcare.

In this thesis, I have presented healthcare professionals' experiences of chronic conditions healthcare, and their creative ways of engaging with the tasks of such work. In doing so, I have highlighted three aspects of chronic conditions healthcare. First, not all healthcare change comes from above, through institutionalised change management. Rather, I suggest that considerable change comes from below, from the grassroots of the actual people doing healthcare. Second, the acute care focus of the healthcare system presents considerable challenges for chronic conditions healthcare. Third, chronic conditions healthcare remains marginalised in culture of healthcare. Finally, I argue that naming and explicitly describing chronic conditions healthcare is an important first step in improving healthcare.

10.1 Swimming in the Stream: A Summary of My Argument

This study has examined what it is like for healthcare professionals to deliver healthcare to people with chronic conditions (longterm diseases and congenital conditions). In the introduction I argued that despite chronic conditions being a dominant healthcare problem of our time, chronic conditions healthcare is largely unexplored. Acute healthcare settings (in particular experiences of hospital rotations) are the traditional training ground for most of modern healthcare education. Ways of responding to chronic conditions have thus been created and structured as branches of acute care models. Healthcare systems are historically and financially focused upon hospital care provision, healthcare professionals do most of their training in hospital settings, and

preventative and community healthcare funding generally draw the short straw when acute (or 'immediate', 'emergency') needs are juxtaposed against longer-term ('chronic'). This results in a number of difficulties for individual healthcare professionals: (1) negotiating patient needs as opposed to system offerings, (2) the increasing prevalence of chronic conditions that require work to 'prevent' or 'monitor' or 'tweak' rather than 'fix', and (3) the lack of recognition for such approaches to healthcare. While epidemiological patterns and healthcare worker demographics are changing, only indirect attention has been paid to the experiences of those who are presently doing chronic conditions healthcare.

An important finding is that chronic conditions healthcare is only intermittently focused upon, and indirectly voiced. Equally, language and terminology for discussing and expressing the complexities and ambiguities of chronic conditions healthcare is in the process of formulation. Nevertheless, healthcare professional participants are assembling expertise in response to longterm conditions. This thesis has presented some of that expertise: participants are beginning to formulate their own definitions of what chronic conditions healthcare should (and should not) include. Chronic conditions healthcare is not yet a clinical specialty in its own right, excepting in some disease-specific models, eg diabetes and asthma educator roles. However, generalist health professionals are to some extent seeing chronic conditions healthcare as a specific subset of their work. Most do chronic conditions healthcare work implicitly and without explicit consideration. However, those who have trained in specific chronic conditions support modes are more intentional about how they do such work.

10.1.1 Summary of the Findings

The second section of the thesis, starting with Chapter Five, began to 'out' chronic conditions healthcare from the complex closet of rural and regional clinician activity. It presented evidence that participants do not explicitly frame up or define what they are doing as chronic conditions healthcare, but that they nevertheless have distinct understandings of various ways of conceptualising chronic conditions healthcare. Chapter Five explored different participant ways of defining chronic conditions healthcare: through definitions which resulted from quantifying the amount of chronic conditions healthcare, through examples of practice, and through subtleties of what they perceived as the nature of chronic conditions healthcare. In the second half of the chapter, results suggest that people who do chronic conditions healthcare are in the process of gathering particular ways of describing their activities into emerging different rhetorics, but presently generally describe their work via language from other healthcare sub-disciplines. Examples of how various sub-disciplines influence chronic conditions healthcare

followed. Some participants use chronic conditions specific languages and rhetorics based on specific chronic conditions care models (eg chronic conditions self-management support frameworks). However, as Chapter Five illuminates, others use languages and skillsets obtained through other more clearly defined healthcare fields. Participants are taking inspiration and strategies from community healthcare, primary healthcare, aged care, palliative care, midwifery, intensive care, aboriginal healthcare, and complementary therapies. These provide day to day strategies for working with people with longterm conditions. The chapter concluded with a brief discussion of how these definitions and descriptions (or lack of definition) typify the present status of chronic conditions healthcare, and set the scene for Chapter Six.

Chapter Six highlighted some actual strategies (techniques and tactics) which participants named as useful in doing chronic conditions healthcare. These included:

- 'being with' the individual (journeying alongside the patient in their individual chronic conditions illness experience and trajectory)
- partnering with the patient (in ways which are often not possible in acute condition circumstances),
- working one step at a time (or 'just small steps'),
- working systematically,
- maintaining flexibility,
- highlighting what is going well (both in healthcare and selfcare),
- reinforcing and nurturing independence and autonomy (including self-management),
- working holistically with each individual (including family, friends and environment where relevant), and
- taking the time (to deal with the normal complexity of chronic conditions).

All were considered necessary and useful strategies for chronic conditions healthcare. Different participants emphasized different aspects. However all demonstrated a range of the above techniques when observed or filmed, and in discussion during interviews. Techniques were drawn from multiple sources, including other kinds of healthcare and from spiritual as well as professional practices. Participants suggested that having these ways of thinking and behaving made doing chronic conditions healthcare both easier and more satisfying. Using some or all of the tactics appeared crucial to personal sense of efficacy and satisfaction within such work. It became apparent that clinicians are creating effective chronic conditions healthcare by making incremental changes in healthcare practice within existing healthcare structures. Through "appropriating, resisting and hybridising" (Dombroski 2012, p. v) existing professional care-

giving practices, participants created their own ways of doing chronic conditions healthcare. Such findings suggest that chronic conditions healthcare is a distinct entity which requires a different kind of engagement across different time-frames, different tactics, and some re-focusing and hybridising of tactics learnt elsewhere.

This thesis has also examined some of the external factors shaping present-day chronic conditions healthcare praxis. Chapter Seven explored how environmental factors such as funding, role structures, and experiences outside work contexts (personal experiences and motivations) are affecting participants' ways of doing chronic conditions work. While some environmental factors enable and make possible good chronic conditions healthcare, others constrain or problematize chronic conditions healthcare. Funding paradigms, logic and inflexibility were generally perceived as constraints in constructing how healthcare professionals are enabled to approach chronic conditions healthcare; and professional as well as personal roles (particular profession and/or social expectations) both facilitated and constrained how participants do chronic conditions work. Participants also clearly connected their personal experiences with their present work motivations and attributes. Personal experiences (of either their own or immediate family members/friends' chronic conditions), as well as personal motivations, partly determined how much, as well as in what way, participants actually went about doing chronic conditions healthcare. Participants were doing chronic conditions healthcare 'because it's there' or 'because I'm needed', and for its intrinsic interest ('it's fascinating'), but also through utilising personal healthcare experiences and (for some) the support of spiritual beliefs. Contextual factors such as rurality also influenced how participants do chronic conditions healthcare. Increased rurality provides increased autonomy, increased capacity for care continuity, and increased ability to personalize care. However increased rurality also reduces some care options and access, through increased waiting times or unavailability of specialist medical or allied health support. Funding, professional roles, environmental cultures, and personal experiences all contribute to the creation of informal practice patterns; clearly influencing the types and styles of work. This was summarized through the conceptualisation of 'social determinants of clinical care', as an important concept in understanding chronic conditions healthcare.

10.2 Achieving the research aims and addressing the research question

This thesis has addressed the question:

What is it like, and what does it mean, to be a health professional doing chronic conditions healthcare?

It has provided rich detail about "concrete, little things" (Flyvbjerg 2006, p. 238), which together express what it is to be a clinician doing chronic conditions healthcare. It also significantly strengthens the chronic illness justice narrative. By providing clinician perspectives on the experience of doing chronic conditions healthcare, it augments the calls of Larsen, May, Charmaz and others (as discussed in Chapters One and Two); for issues surrounding chronic conditions to be given equal attention alongside other voices. Whilst cancer, suicide, and road accidents dominate media discourse, evidence provided in this thesis demonstrates a quiet groundswell of chronic conditions activity in the healthcare landscape. There is extensive clinician engagement in a different kind of healthcare work, which provides sufficient "force of example" (Flyvbjerg 2006, p. 228) that a new healthcare sub-discipline and field of study needs be conceptualised. The branding of 'chronic conditions healthcare' as a new healthcare entity, on par with palliative care, midwifery, aged care, emergency care, Aboriginal health and so on, could generate the kind of intellectual and advocate energy we have seen generated by specific Chairs and Departments of such disciplines. By retaining a broad rather than disease-specific focus, a chronic conditions healthcare discipline could encourage system-designing from pattern to detail (rather than the present largely reverse attempts), integrating rather than segregating disease-specific approaches into broadly transferrable skills. Further study is required into how it is that healthcare professionals actually accomplish chronic conditions healthcare, and what systemic strategies and tactics may further aid them.

10.3 Contributions of this research

As far as I am aware, this research is the first doctoral level in-depth exploration of chronic conditions healthcare across multiple disciplines: an iterative investigation of a previously unexplored phenomenon. It utilises multiple qualitative data acquisition methods alongside thematic analysis, utilising a novel method (video-triggered interviews) to add depth and integrity alongside the traditional qualitative observations and semi-structured interviews. Economic, political, social and cultural factors affect clinicians and their doing of chronic conditions healthcare; and qualitative research can provide powerful information to assist in the understanding of "context issues that have become the concern of public health in recent years" (Baum 1995, p. 464). At a time when chronic conditions are gaining increasing focus, it is important to examine health professionals' experiences, both of the cultural contexts of healthcare work, and of chronic conditions healthcare itself.

In providing clinician perspectives on the experience of doing chronic conditions healthcare, this thesis augments the calls of others; for issues surrounding chronic conditions to be given equal

attention alongside other more dominant voices. However it also contributes a previously untold 'story', exposing the hidden nature of chronic conditions healthcare.

This thesis presents one of a number of possible versions of reality: a social construction dependent on a particular presentation, from one particular version of my own 'being-in-the-world'. As a writer situated between a number of differing theoretical and practical fields, I have assembled a text drawn together from multiple trajectories; creating an argument, research design and fieldwork which could easily have been otherwise. As with all research and writing processes, "some of the decisions of enactment were intentional, deciding what realities to enact as 'more real', [however] much of the way things turned out was responding to contingencies" (Dombroski 2012, p. 271). In presenting multiple perspectives, experiences, and ideas, whilst simultaneously crafting a coherent argument, I have demonstrated that research, like other intentional activities, must respond to the demands and suggestions presented en route. This thesis is one manifestation of the experiences of fieldwork and writing: it demonstrates some of a number of possible worlds.

10.3.1 Limitations of the research

As this is a small project with a multi-discipline sample and small numbers of each profession, it is not possible to do a rigorous comparison of different professional outlooks within this research. However there were clear indicators that different professions approached particular tasks or approaches within chronic conditions healthcare in different ways. For example, the same kind of diabetic reviews could be done by GPs, practice nurses, nurse practitioners, or diabetes educators; however each approached this task in slightly different ways. Equally, mental health assessments were another task which might be carried out by GPs, nurses, social workers, psychologists or occupational therapists, who, despite having the same checklist, might come to slightly different conclusions and/or treatment recommendations. Further investigations of the effects of different disciplinary backgrounds on chronic conditions healthcare are required.

The research also explored the interconnectedness of clinicians' personal identities and professional work histories with their chronic conditions healthcare approaches. Three broad aspects of personal experience (1) participants' own chronic conditions, (2) their significant others' experience of chronic conditions (for example, children, partners, parents or siblings with chronic conditions), and (3) their workplace experiences of chronic conditions all appear to impact significantly on how participants do chronic conditions healthcare. Each of these areas, separately explored, could yield further information.

10.3.2 Contributions of the research

This study contributes to the larger body of research which suggests that healthcare is at a crux, and where critique is meant to "work towards something, rather than away from something in the form of mere deconstruction" (Dombroski 2012, p276). The main contribution of this thesis is to demonstrate intensive clinician engagement in an emerging kind of healthcare work. On the basis of evidence presented in this thesis, I argue that chronic conditions healthcare needs to be named up, described, and bounded; as a preliminary step towards improving our approaches to chronic conditions healthcare. More evidence is required to fully support an argument for chronic conditions healthcare to become a separate healthcare speciality new discipline. However, it is possible that chronic conditions healthcare could make a shift: in the same way that intensive care and palliative care moved from being un-named subsets within more generalist healthcare, to specialist forms of healthcare applicable to multiple illnesses. Present epidemiological profiles alongside patient demands and advocacy may enable chronic conditions healthcare to become a professional area of specialisation in its own right. A larger survey could provide further evidence to support this conclusion.

Methodological

Methodologically, this thesis contributes a new exemplar of a type of video-based ethnography to chronic conditions healthcare research. Effective across a range of clinical settings, the small sample of video-triggered interviews in this study offered willing participants an opportunity to see themselves at work, and to reflect on their clinical practice more broadly as well as their chronic conditions approaches. Whilst, due to financial and physical resource constraints, the video-triggered interviews remained a small portion of the total data, the material gathered through this method was particularly insightful and influential on the development of later (non-video-recorded) observations and interviews. I believe that further studies using this method would be worthwhile.

Additionally, this research contributes a multi-discipline perspective, valuing all healthcare professions as contributing to the present picture of chronic conditions healthcare. By describing similarities and differences between professions as well as individuals, this research reinforces the commonalities as well as the distinctions between the diversity of health professions doing chronic conditions healthcare.

Understandings of Healthcare Professional Agency

Healthcare professional participants presently maintain agency in a number of subtle and less-so ways. Participant ways of getting, maintaining, or creating agency included getting out of hospital

(or more hierarchical) contexts; working in solo operator rather than team contexts; and/or working part-time.

For some participants, community based work generally meant one on one work with a patient, with limited or intermittent supervision, and considerable freedom to develop an individual style of practice. Most of the research participants had found ways of doing extremely personal styles of healthcare, often through synthesis of previous work approaches. All of the participants appeared to have found a style of doing chronic conditions healthcare which worked for them, although some aspects of their way of working may or may not have been considered orthodox by other participants. For some participants, moving out of more hierarchical contexts (eg setting up their own one-person practice, and later taking on staff as their practice grew), and working more in community than in institutional settings, was helpful in maintaining a sense of control of their work and working hours.

Some specialist healthcare professionals working within and alongside hospital contexts had clearly found ways of maintaining their independence within hospital environs. By engaging with hospital systems on their own terms, for example as part-time workers, they enabled their own sense of control over and availability for chronic conditions healthcare work.

Part-time work was a common tactic. For some, workforce participation was largely determined by their personal caring responsibilities (for children or elders). Others specifically named part-time work as part of their personal approach to managing the intensity of healthcare work. Some chose to specialise in particular chronic conditions fields within their generalist practice intake (self-management support, asthma, depression or diabetes), whilst others preferred diversity of clientele; in order to pace themselves within working hours.

Agency, within an age of increasing workplace choice, appears an important area for further chronic conditions healthcare research.

Assemblage (hybridisation) theory of chronic conditions healthcare

This thesis has demonstrated that participants are assembling hybrid theories and praxis in attempts to both comprehend and actually do chronic conditions healthcare. Choosing from the range of healthcare activities and techniques to which they have been exposed during their undergraduate and professional careers, and leavening their styles of practice with personal as well as professional motivations, participants have generally synthesized their own personal way of working within structural (healthcare system) and individual (patient preference and present

capacity/s) constraints. If we understand healthcare as an assemblage, we can better understand the complex ways in which individual practice styles and coping strategies develop, through interactions with individuals, colleagues, training opportunities, career paths, and cultural mores. This is the case for chronic conditions healthcare as much as for any other healthcare discipline.

10.4 Beginnings and Endings

Like most research, this thesis ends where it began: "in a place of not-knowing" (Dombroski 2012, p. 286). I began this research as a pregnant thirty-two-year-old, expecting a collaborative project within a DHHS-nested research collective. I ended the research with a genuine interest in and passion for chronic conditions healthcare, and for helping health professionals to find their way towards more satisfying chronic conditions encounters. Whilst the work of disseminating the results of the research is largely just beginning, the encounters with healthcare professionals along the way have been influential for some of them as well as for me.

Nevertheless, there is much work to be done. Chronic conditions healthcare is not known, and not well understood within clinical professions, even where policy frameworks suggest otherwise. I argue that while possibly 'less sexy'[21], chronic conditions healthcare is a distinct subset of clinical work with particular tactics and evolving rhetorics. Klein suggests that present healthcare funding arrangements are inherently biased, "against talking to people [patients] and for cutting, scanning and chopping into them" (Klein 2013). Further study is required into how it is that healthcare professionals actually accomplish chronic conditions healthcare, particularly in primary healthcare settings; and what systemic strategies and tactics may further aid them.

In any health era, clinical change must follow epidemiological and societal variation. This thesis describes societal and clinical changes already happening from the perspective of individual clinicians, through a mixture of resistance, acquiescence, appropriate and subversion. However, such changes are presently largely implicit and not well understood (nor always well supported). Participants' chronic conditions healthcare tactics are evolving: in response to increasing volumes of chronic conditions work, broader societal changes (including the increased autonomy of patients), the ageing of workforces and clienteles, and the feminization of the healthcare workforce as a whole. These social changes affect healthcare work as a whole, but chronic conditions healthcare in particular.

[21] "things which are important but nevertheless fail to get the attention they deserve" (Sandelowski 2000, p. 334).

Chronic conditions healthcare is a separate entity which deserves further attention. In the same way that a relationship with a midwife can be 'special' to mothers (Wilkins 2000, p. 29), and a palliative care team is appreciated by a patient and their family (Kellehear 1999), a relationship with one or more chronic conditions healthcare professionals can be special to chronic conditions patients. However, without a shared vocabulary or recognisable professional community, people who do chronic conditions healthcare presently practise in independent silos: individually 'invent the wheel', rather than replicate effective models. Primary healthcare is still struggling to gain public and professional comprehension and accessibility. However, it is possible that the creation of chronic conditions healthcare as a distinct entity and sub-discipline could enable more direct focus, active management, and system planning; for what presently occupies a substantial amount of primary healthcare time. We need chronic conditions healthcare to occupy a central place in primary, secondary and tertiary healthcare; rather than occur through reactive happenchance.

In a postmodern society, choices are identity statements - "complex and contingent interactions between multiple trajectories, modernities and realities" (Dombroski 2012, p. 271). In this context, not only patients', but also health professionals' personal and professional choices and identities construct chronic conditions healthcare. We need to prioritise not only biomedical and intellectual understandings of chronic conditions and chronic conditions healthcare, but also social and emotional understandings and ways of doing chronic conditions healthcare. In seeking community views on healthcare, we need also understand that healthcare workers are a part of either the same or similar communities, and subject to the same influences: ie changing demographics, ageing populations, and more individualistic and risk averse cultures. Long-term condition healthcare workers, as well as patients, are independent actors; with varying levels of agency which often determine what does and doesn't happen in healthcare. Having an ageing parent may negatively affect work availability, whilst positively influencing knowledge of available local resources, and empathy for both patient and carer journeys. The cultural, physical and emotional environments of healthcare professionals are crucial to how much chronic conditions healthcare is done, and in what ways. With more direct attention to chronic conditions healthcare, our healthcare professionals and systems can be primed, trained, and planning to swim long distance rather than short course events. With attention to chronic conditions healthcare, workers can swim more strongly through the ever present stream of chronic conditions, towards the aims of the Alma Ata Declaration (1978) and Ottawa Charter (1986): health and wellbeing - as each of us define it - for all.

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Appendix 1: Participant Information and Consent Forms

A. Health Professional Invitation to Participate

Being a Rural Health Professional and Working with People with Chronic Conditions

INVITATION TO PARTICIPATE
IN HEALTH AND MEDICAL RESEARCH

Dear Health Professional,
You are invited to participate in a research study into being a rural or remote health professional and working with people with chronic conditions.

What is the purpose of this study?
This study will investigate the experience of being a rural health professional[22] at a time when work with chronic conditions[23] is increasing. Chronic condition management is a task undertaken by both health professionals and patients, however in this study, we are interested in

- how working with chronic rather than acute conditions intersects with rural and remote health professional role/s (job descriptions and system structures), and
- how working with chronic rather than acute health issues affects rural and remote health professionals' identities (personal perspectives of yourself as health professional in rural and remote communities).

Why have I been invited to participate?
You have been sent this invitation because you have been identified by your employer or by a colleague as a health worker in rural, remote or regional Tasmania.

Who is doing the research?
The study is being conducted by:

Anna Spinaze	PhD Candidate (Partners in Health Scholarship DHHS/UTas), University Department of Rural Health, University of Tasmania

under the supervision of:

Dr Sue Kilpatrick	Associate Professor (Rural Health), Director, University Department of Rural Health, University of Tasmania

[22] In this study, health professionals include any tertiary educated health related profession, and may include GPs, community nurses, practice nurses, and allied health professionals (diabetic educators, physiotherapists, radiographers, psychologists, social workers, paramedics, naturopaths, etc). Paraprofessionals (for example enrolled nurses) who are interested may also be eligible. If you see yourself as a health professional who works in a rural or remote area or with rural and remote clients we are interested in interviewing you. Please contact us if you wish to discuss eligibility.

[23] In this study, 'chronic conditions' are defined as any physical or mental illness, disease or disability, which affects long-term health; and 'chronic conditions work' any health work with people with chronic conditions. We are equally interested in your work with patients who consider their chronic condition to have minimal impact on their lives, and with those who find life more difficult; and with work on status maintenance (maintenance or improvement of health and wellbeing given existing condition, prevention of exacerbations, health promotion etc) as well as acute manifestations. Examples of chronic conditions include (but are not limited to) asthma, diabetes, arthritis, high blood pressure, depression and ongoing back pain.

Dr Doug Ezzy	Associate Professor (Sociology), Deputy Head School of Sociology and Social Work, University of Tasmania

The research project has been given ethics approval by the Tasmanian Health and Medical Human Research Ethics Committee, reference number H0010036.

What does this study involve?
If you agree to be involved, there are a number of ways to participate. Phase 1 includes observation of your daily work. Phase 2 involves filming a normal service encounter or appointment between yourself and a patient with chronic condition/s whom you nominate. Phase 3 involves being interviewed about your role and identity as a rural health professional, and may include viewing your footage from Phase 2. You can volunteer to participate in any or all of the above phases (however numbers for each phase will be limited).

More information about each of the above phases is available as part of a Participant Information Package, which includes a more detailed Information Sheet, Patient Information Sheet and Patient Consent Form.

All fieldwork will take place generally between June 2008 and June 2010, at a place and time you select. After fieldwork is complete, further analysis and member checks (consulting participants as to the accuracy of findings) will be conducted. The research will contribute to completion of a PhD thesis (projected submission September 2012) and associated publications. All information will remain confidential and no volunteers' names or faces will appear in any publication connected to the research.

How do I get involved?
If you are interested in being involved in this research, please contact Anna Spinaze.

You can contact her by email (preferred) to anna.spinaze@utas.edu.au, by writing to her c/- PO Box 233, Cygnet, 7112, or by telephoning 6297 8399.

Alternatively, there is a "Research Expression of Interest" page attached, which lists the options for each phase. Please mark those you are happy to be involved in, and return to anna.spinaze@utas.edu.au, or simply contact me.

RESEARCH EXPRESSION OF INTEREST

Being a Rural Health Professional
and Working with People with Chronic Conditions

I understand that the study involves the options below, and have ticked the boxes to indicate those parts of the research I am interested in being involved in:

Phase 1: observation (with researcher taking notes)

work day	Yes ☐	No ☐
out-of-hours work	Yes ☐	No ☐
*optional still photography**	Yes ☐	No ☐
*optional filming**	Yes ☐	No ☐

Phase 2: filming of a normal encounter between myself as health professional with a chronic condition/s patient of my choice

Yes ☐ No ☐

Phase 3: interview about role and identity and working with chronic conditions

interview	Yes ☐	No ☐
interviewing watching film from Phase 2	Yes ☐	No ☐

I understand that sending in this Expression of Interest does not necessarily commit me to being involved in this research, nor commit the researchers to involving me.

Name:

Profession / Position:

Contact Details: (ph / email preferred):

**no patients in field of vision*

B. Health Professional Participant Information Sheet

Being a Rural Health Professional and Working with People with Chronic Conditions

PARTICIPANT INFORMATION SHEET
HEALTH AND MEDICAL RESEARCH

What is the purpose of this study?
This study will investigate the experience of being a health professional[24] in rural and remote areas at a time when work with chronic conditions[25] is increasing. Chronic condition management is a task undertaken by both health professionals and patients, however in this study, we are interested in

- how working with chronic rather than acute conditions intersects with rural and remote health professional role/s (job descriptions and system structures), and
- how working with chronic rather than acute health issues affects rural and remote health professionals' identities (personal perspectives of yourself as health professional in rural communities).

Why have I been given this Information Sheet?
You have been sent this information sheet either because you have expressed interest in this research project, or because you have been identified by your employer or by a colleague as a possible participant. Participation is open to health professionals working in rural, remote and/or regional Tasmania.

Who is doing the research?
The study is being conducted by:

Anna Spinaze	PhD Candidate (Partners in Health Scholarship DHHS/UTas), University Department of Rural Health, University of Tasmania

under the supervision of:

Dr Doug Ezzy	Associate Professor (Sociology), Head of School of Sociology and Social Work, University of Tasmania
Dr Peter Orpin	University Department of Rural Health, University of Tasmania
Dr Sue Kilpatrick	Pro Vice-Chancellor (Rural and Regional), Deakin University

This study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee, reference number H0010036.

What does this study involve?
If you agree to be involved, there are a number of ways to participate. Phase 1 includes observation of your daily work. Phase 2 involves filming a normal service encounter or appointment between yourself and a patient with chronic condition/s whom you nominate. Phase 3 involves being interviewed about your role and identity as a rural health professional, and may include viewing your footage from Phase 2. You can volunteer to participate

[24] In this study, health professionals include any tertiary educated health related profession, and may include GPs, community nurses, practice nurses, and allied health professionals (diabetic educators, physiotherapists, radiographers, psychologists, social workers, paramedics, naturopaths, etc). Paraprofessionals (for example enrolled nurses) who are interested may also be eligible. If you see yourself as a health professional who works in a rural or remote area I am interested in interviewing you. Please contact Anna Spinaze if you wish to discuss eligibility.

[25] In this study, 'chronic conditions' are defined as any physical or mental illness, disease or disability, which affects long-term health; and 'chronic conditions work' any health work with people with chronic conditions. We are equally interested in your work with patients who consider their chronic condition to have minimal impact on their lives, and with those who find life more difficult; and with work on status maintenance (maintenance or improvement of health and wellbeing given existing condition, prevention of exacerbations, health promotion etc) as well as acute manifestations. Examples of chronic conditions include (but are not limited to) asthma, diabetes, arthritis, high blood pressure, depression and ongoing back pain.

in any or all of the above phases (however numbers for each phase will be limited). More detail of each phase is below.

The research options are as follows:
Phase 1: observation
Involves ethnographic **observation of a working day**, possibly extending to out-of-hours work. With additional consent, some ethnographic filming of you and/or your work environment may take place.

During Phase 1, the researcher (Anna Spinaze) will be observing your general day-to-day practice (settings, people, time, context, activities), gaining a sense of the kind of range and breadth of your work, and the differences between working with acute and chronic conditions. She will observe you from when you arrive at work until you 'finish' for the day, as if she were an undergraduate health profession student. Where possible, she would like to observe during consultations (with patient permission), as well as in-between (corridor work, reception areas etc). A sign will be provided for your workplace reception area stating: "Health Professional X has a researcher observing them today. Please tell the receptionist or Health Professional X if you would like more information or do not want the researcher present during your consultation." If you are undertaking house calls, out of hours work, or community based work, the researcher will remain outside the venue until you or your patient/s invite her in.

Notes will be taken intermittently during observation periods. Still photographs or filming will only be taken during observation periods after asking additional (on the spot) permission, and will not include patients in field of vision. Field notes, photographs and footage will be kept strictly confidential (in locked cabinets / on password protected computers), and no identifying material from fieldwork will be used in discussions or publications.

Phase 2: filming a consultation or service encounter
You will be asked to recruit one of your ongoing patients with a chronic condition, in order to **film a normal consultation / service encounter between yourself and that patient**. The purpose of taking footage is to enable detailed observation of chronic conditions work, to compare different professional and different professions approaches, and to enable detailed analysis of the differences between acute and chronic conditions healthcare.

A separate invitation cum information sheet and consent form will be provided for you if you agree to participate in this phase, to give to prospective patient participants. Please contact us if you would like to discuss the kind/s of patient you may prefer to recruit.

After choosing a chronic condition/s patient you think suitable, we would appreciate it if you could contact them in advance, explaining verbally the general aims and requirements for them as per the Patient Research Invitation and Information Sheet (single document). Please emphasize to them that the research focus is on yourself, that their potential participation is strictly voluntary, and that withdrawal or refusal to participate will not affect either their treatment or their relationship with you as healthcare provider.

If they are agreeable, please ask them to come a little earlier to the relevant appointment in order to read the Patient Research Invitation and Information Sheet and sign the Consent Form, and also to allow time for viewing footage of the appointment immediately afterwards if they wish. Please also *notify the researcher as soon as possible of that appointment date, location and time*. Wherever possible the researcher will make themselves available for this date and time, however it is possible that this may need to be negotiated according to researcher availability.

On an agreed date, with formal (written) consent of both you and your patient, prior to appointment time a camera will be fixed aiming at your normal consultation area, and switched on prior to commencement of the consultation. The camera will be positioned so that audio recording can continue but intimate physical examination would be obscured. No researcher will be in the room with you during the consultation (unless requested), and before the patient enters for the consultation the researcher will explain to both you and your patient how to stop recording. After the patient leaves the room, the researcher will enter briefly, stop the camera, and remove it from the room. They will then re-confirm that you and your patient consent to research use of this footage, and verbally offer the patient the opportunity to watch the unedited footage immediately. You will be offered access to unedited footage in your own time, as well as to excerpts from the footage within Phase 3 if you participate in Phase 3.

You and your patient will have the right to change the above filming conditions to better suit you or your work conditions (for example if you are working within a patient's home, or you wish the researcher to film directly rather than leaving the room). Video-filming will, if possible, be stopped in situations of crisis, and inappropriate data will be destroyed.

Any information obtained in connection with this project and that can identify participants will remain confidential. No information that will identify participants is made public. For the purposes of privacy law (the *Health Records and Information Privacy Act 2002)*, sensitive information includes personal information (i.e. information or an opinion about a patient) and all other health information. We will treat the patient information recorded on film as sensitive information as per this legal requirement, and will not compromise the patient's care.

Phase 3: interviewing
Phase 3 involves an **individualized semi-structured interview**, using a theme list investigating your experiences of working in rural / remote areas with people with chronic conditions. Interview material would include discussion of both your role/s (job description/s and structures), and your more personal experience of this in rural/remote communities (your identity/s). Interviews will be audio taped and transcribed for the purposes of analysis.

If you have been involved in Phase 2 and you are part of Phase 3, you may be shown footage of yourself working with the patient you selected as part of the interview. This interview will be audio-recorded and/or video-recorded, and transcribed for the purposes of analysis.

If you have not been involved in filming, a semi-structured interview addressing similar material to that covered in film-based interviews will be conducted. The interview *may* include footage of other (de-identified) footage of other health professionals working with (de-identified) chronic condition patients. This interview will be audio-recorded and/or video-recorded, and transcribed for the purposes of analysis.

Research Logistics
All research will be conducted at your convenience, at your workplace, or, in the case of interviews, in your workplace or any other place mutually agreed. Where you choose to participate in Phase 2 and Phase 3, interviews will take place as soon as possible after the filmed consultation (ie within the one fieldwork visit). While we expect most interviews to take up to an hour, some interviews may not be finished in this time. In this case the participant may choose whether the researcher continues or comes back at another time for further interview.

Fieldwork will take place between July 2008 and July 2010. After fieldwork is complete, further analysis and member checks (consulting participants as to the accuracy of findings) will be conducted, and the thesis written and ready for submission by September 2012.

Please note that you may not necessarily choose to or be asked to participate in all phases of this research. Please also note that research participation is both possible and encouraged with or without involvement in filming.

Voluntary Nature of Research
It is important that you understand that your involvement is this study is voluntary. While we would be pleased to have you participate, we respect your right to decline. There will be no consequences to you if you decide not to participate, and this will not affect your work prospects or your patients' treatment. If you decide to discontinue participation at any time, you may do so without providing an explanation. All information will be treated in a confidential manner, and no identifiable text or pictures revealing you or your name, or those of your patients, will be used in any publication arising out of the research. All of the research will be kept in a locked cabinet, or on password protected computors.

Are there any possible benefits to me from participation in this study?
Both the presence of the researcher and the process of participating in research may provoke reflective self-analysis, and many people find the opportunity to 'tell their story' in an interview both enjoyable and informative. Many people find viewing footage of themselves particularly interesting. When the study is finished we hope to put the results to practical use in improving workforce design and training, and thereby recruitment and (in particular) retention rates of rural and remote health professionals.

All filming is intended to function both as research data for this project and if you wish, as a potential tool for self-reflection on your own day-to-day practice. In an effort to facilitate this, participants in Phase 2 will be offered access to the (unedited) footage of themselves, for a period of one month after initial filming. *If you would like to view the footage, please notify the researcher as soon as possible.* Please note however that provision of access to footage is for your interest only, is not provided as part of any formal training method, and does not necessarily contribute toward any formal professional development program.

Publications and the thesis which result from the study will be available through the University Department of Rural Health. Participants are welcome to contact Anna Spinaze for an update on research progress during her candidature.

Are there any possible risks to me from participation in this study?
There are no specific risks anticipated with participation in this study. There is a slight risk(s) of emotional discomfort, embarrassment or upset, due to discussion of past or present experiences and filming/viewing footage of your day-to-day work practice. However, if you find that you are becoming overly embarrassed, distressed or uncomfortable due to participating in the research, please tell the researcher and/or contact the Bush Crisis Line (1800 805 391, details below).

All care will be taken during the research process, and any participant will be free to request a break or withdraw from the study at any time if they wish**.** Participants may also withdraw part or all of their research contribution (eg fieldnotes, footage of service encounter or interview recording) within one month from the date of contribution. No copies of footage will be given to patients, however in order to enable informed withdrawal of patient participants from research, they will be offered the opportunity to watch footage of their encounter immediately after the recording session. It is assumed that if the filming protocol has been followed, that no sensitive or difficult areas are likely to have been filmed, and that you or your patient will state immediately when asked after the consultation if you do not want the film viewed. It would then be destroyed immediately. The researcher will be present during any patient playback session, and will encourage patients to address any queries in a subsequent session with their health professional.

Anyone who withdraws from the research or terminates an interview will be offered the opportunity to speak with Dr Doug Ezzy regarding any issues, problems or concerns with the research process.

Participants are encouraged to use the Bush Crisis Line, a twenty-four hour confidential telephone support and debriefing service for multi-disciplinary remote and rural health practitioners and their families. It is staffed by qualified psychologists with remote and cross-cultural experience, is toll free and available from anywhere in Australia. For more information http://www.bushcrisisline.org.au or telephone 1800 805 391.

What if I have questions about this research?
If you would like to discuss any aspect of this study please feel free to contact either Anna Spinaze on ph 6297 8399 or Dr Doug Ezzy on ph 6226 2330. Either of us would be happy to discuss any aspect of the research with you. Once we have analysed the information we will be mailing / emailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote reference number H0010036.

Thank you for taking the time to consider this study.
If you wish to take part, please email anna.spinaze@utas.edu.au or ph 6297 8399.
This information sheet is for you to keep.

Anna Spinaze	PhD Candidate (Partners in Health Scholarship DHHS/UTas), University Department of Rural Health, University of Tasmania
Dr Doug Ezzy	Associate Professor (Sociology), Deputy Head School of Sociology and Social Work, University of Tasmania
Dr Peter Orpin	University Department of Rural Health, University of Tasmania
Dr Sue Kilpatrick	Pro Vice-Chancellor (Rural and Regional), Deakin University

C. *Health Professional Consent Form*

Being a Rural Health Professional and Working with People with Chronic Conditions

HEALTH PROFESSIONAL CONSENT FORM

---

1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves the options below, and have ticked the boxes to indicate those parts of the research I am happy to be involved in:

Phase 1: observation (with researcher taking notes)

work day	Yes ☐ No ☐
out-of-hours work	Yes ☐ No ☐
optional still photography*	Yes ☐ No ☐
optional filming*	Yes ☐ No ☐

*no patients in field of vision

Phase 2: filming of myself as health professional with a chronic condition/s patient

I consent to this encounter being digital video-recorded, transcribed and analysed.
Yes ☐ No ☐

I consent to footage from the above to be shown to myself.
Yes ☐ No ☐

I consent to footage from the above to be shown to said patient.
Yes ☐ No ☐

I consent for footage from the above to be shown to other health professionals, after blurring/pixilating of my face.
Yes ☐ No ☐

Phase 3: interview

I consent to participating in a semi-structured interview, which will be audio-recorded and transcribed for analysis purposes.
Yes ☐ No ☐

I consent to participating in a semi-structured interview, during which I may be shown footage of myself and/or de-identified others at work, which will be audio and/or video-recorded and transcribed for analysis purposes.
Yes ☐ No ☐

4. I understand that participation involves slight risk(s) of emotional discomfort, embarrassment or upset, due to discussion of past or present experiences and filming/viewing footage of my day-to-day work practice. I understand that I can stop filming and withdraw any footage within one month of contribution.
5. I understand that all research data will be securely stored on the University of Tasmania premises for at least five years, and will be destroyed when no longer required.

6. Any questions that I have asked have been answered to my satisfaction.
7. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
8. I understand that the researchers will maintain my identity confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of research.
9. I agree to participate in this investigation and understand that I may withdraw at any time without any effect, and if I so wish, may request that any data I have supplied within the previous month be withdrawn from the research.

Name of Participant:

Signature: **Date:**

Optional: If you would like to be posted or emailed a summary of research findings, please add your address and/or email:

Statement by Investigator

☐ I have explained the project & the implications of participation in it to this volunteer, I believe that the consent is informed, and that he/she understands the implications of participation.

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Investigator:

Signature: **Date:**

D. Patient Participant Invitation and Information Sheet

Being a Rural Health Professional and Working with People with Chronic Conditions

PATIENT INVITATION & INFORMATION SHEET
HEALTH AND MEDICAL RESEARCH

Dear Madam / Sir;
You are invited to participate in a research study into rural or remote health professionals working with people with chronic conditions. This study is being conducted by Anna Spinaze, with Chief Investigator A/Prof Sue Kilpatrick and Co-Supervisor A/Prof Douglas Ezzy, as part of a postgraduate doctorate of philosophy program through the University of Tasmania. Anna is a former medical student who has worked as a research assistant on various health and social research projects since 2003.

What is the purpose of this study?
This study will investigate how different healthcare professionals experience working with chronic conditions in rural and remote Tasmania. Chronic condition management is a task undertaken by both health professionals and patients, however in this study, we are interested in

- how health professionals find working with chronic rather than acute conditions intersects with their professional role/s (job descriptions and system structures), and
- how working with chronic rather than acute health issues affects their identity (their perspectives of themselves as health professionals in rural and remote communities).

In exploring these issues, we hope to complement current research on how increases in chronic conditions are affecting health systems and professionals. When the study is finished we hope to put the results to practical use in improving workforce design and training, and thereby recruitment and (in particular) retention rates of rural and remote health professionals. Improving numbers of rural and remote health professionals available is aimed at improving rural and remote patient access to healthcare.

Why am I being invited to be involved?
You are invited to participate because your health professional has volunteered to be part of the research, and as part of the research is going to be filmed working with a patient of theirs who has a chronic condition/s. Your health professional has suggested that you may be interested and appropriate to help with this part of the research. You are eligible to help if you are a person with a chronic condition who consults regional, rural or remote Tasmanian health professionals.

Please note that 'chronic condition' does not necessarily mean you have a serious illness. In this study, "chronic conditions" are defined as any physical or mental illness, disease or disability, which affects longer-term health. Chronic conditions are not necessarily serious or permanent, but range from inconvenient to very difficult or problematic. Examples include (but are not limited to) asthma, diabetes, arthritis, high blood pressure, depression and ongoing back pain. We are equally interested in the work of healthcare professionals with patients with minor but ongoing conditions as well as serious conditions. If, as a patient, you consider you do not have a chronic condition, you would not be eligible to participate in this research. Please talk with your healthcare professional or contact Anna Spinaze if you wish to discuss eligibility.

Your involvement
Your involvement, if you consent, would be to allow digital video recording (filming) of a consultation between yourself and your healthcare provider.

This film will be used during an interview with your healthcare provider. If you grant additional permission, footage may also be shown to other healthcare providers, after blurring/pixilating of your face to obscure identity. Your own healthcare provider may view unedited footage for self-education purposes.

If you and your health professional consent, prior to appointment time a camera will be fixed aiming at the normal consultation area, and switched on prior to commencement of the consultation. The camera will be positioned so that audio recording can continue but physical examination can be obscured. No researcher will be in the room with you during the consultation (unless requested), and you and your health professional will have capacity to stop recording at any time.

All filming will take place at your convenience, in a place chosen by yourself and your health professional. In order to enable informed consent/withdrawal and an opportunity to express any concerns, you are offered the opportunity to view the footage of your consultation immediately after filming. *If you would like to view the footage, please notify the researcher as soon as possible.* You and your health professional would have the right to change the above filming conditions to make a film of your encounter which better meets with your satisfaction (for example if the encounter happens at home rather than in a clinic, or you wish the researcher to film directly rather than leaving the room). Filming (and subsequent interviewing of health professionals using the film) will generally take place between July 2008 and July 2010.

Voluntary Nature of Research, and Freedom to Refuse or Withdraw
It is important that you understand that your involvement is this study is voluntary. While we would be pleased to have you participate, we respect your right to decline. **There will be no consequences to you if you decide not to participate, and declining to participate will not affect your treatment or your relationship with your healthcare provider.**

If you decide to discontinue participation at any time, you may do so without providing an explanation. You can also choose to remove some or all of any research material (film footage) you provide within one month of filming. Anyone who withdraws from the research or terminates a filming session will also be offered the opportunity to speak with A/Prof Sue Kilpatrick regarding any issues, problems or concerns with the research process.

Confidentiality of Research
All information will be treated in a confidential manner, and neither identifiable pictures of you nor your name will be used in any publication arising out of the research. All of the research will be kept in password protected computers and a locked cabinet in the office of the University Department of Rural Health.

Benefits, costs and risks of participation
There are no costs, and no specific risks anticipated with participation in this study. There is a slight risk of emotional discomfort, embarrassment or upset, due to discussion of past or present health and illness experiences and filming/viewing footage of yourself. The kind of treatment and care you receive are unlikely to change as a result of participation in this study. Results of the study may or may not have direct benefit to participants.

All care will be taken during the research process, and any participant is free to request a break or withdraw from the study at any time if they wish**.** If you find that you are becoming overly embarrassed or distressed by participating in the research, please tell your healthcare professional and/or press 'stop' as shown on the recording equipment.

If distressed, participants are encouraged to use Lifeline, a twenty-four hour confidential telephone support service which is toll free and available from anywhere in Australia. For more information http://www.lifeline.org.au or telephone 13 11 14.

Publications and the thesis that result from the study will be available through the University Department of Rural Health. Participants are welcome to contact Anna Spinaze for an update on research progress during her candidature.

What if I have questions about this research?
If you would like to discuss any aspect of this study please feel free to contact either Anna Spinaze on ph 6297 8399 or A/Prof Sue Kilpatrick on ph 6324 4000. Either of us would be happy to discuss any aspect of the research with you. Once we have analysed the information we will be mailing / emailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

This study has been approved by the Tasmanian Health and Medical Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0010036.

Thank you for taking the time to consider this study.
If you wish to take part in it, please email anna.spinaze@utas.edu.au or ph 6297 8399.
This information sheet is for you to keep.

Anna Spinaze	PhD Candidate (Partners in Health Scholarship DHHS/UTas), University Department of Rural Health
Dr Sue Kilpatrick	Associate Professor (Rural Health), Director, University Department of Rural Health
Dr Doug Ezzy	Associate Professor (Sociology), Deputy Head School of Sociology and Social Work

E. Patient Participant Consent Form

Being a Rural Health Professional and Working with People with Chronic Conditions

PATIENT PARTICIPANT CONSENT FORM

---

1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves filming an appointment between a rural / remote health professional and myself.

   I consent to this encounter being digital video-recorded, transcribed and analysed.

   Yes ☐ No ☐

   I consent to footage from the above to be shown to myself.

   Yes ☐ No ☐

   I consent to footage from the above to be shown to said health professional.

   Yes ☐ No ☐

   I consent for footage from the above to be shown to other health professionals, after blurring / pixilating of my face.

   Yes ☐ No ☐

4. I understand that participation involves slight risk(s) of emotional discomfort, embarrassment or upset, due to discussion of past or present experiences and filming/viewing footage of my appointment with a health professional. I understand that I can stop filming and withdraw any footage within one month of contribution.
5. I understand that all research data will be securely stored on the University of Tasmania premises for five years from publication, and will be destroyed when no longer required.
6. Any questions that I have asked have been answered to my satisfaction.
7. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
8. I understand that the researchers will maintain my identity confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of research.
9. I agree to participate in this investigation and understand that I may withdraw at any time without any effect, and if I so wish, may request that any data I have supplied within the previous month be withdrawn from the research.

(please sign over)

Name of Participant:

Signature: **Date:**

Optional: If you would like to be posted or emailed a summary of research findings, please add your address and/or email:

Statement by Investigator

☐ I have explained the project & the implications of participation in it to this volunteer, I believe that the consent is informed, and that he/she understands the implications of participation.

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Investigator:

Signature: **Date:**

Appendix 2: Interview Guides (early & final versions)

A. Multi-Profession Interview Schedule (Version 2, 18-8-2008)

1. basic demographics – age, sex, nationality, place affiliation

    - age
    - gender
    - birth order, sexual identity if disclosed
    - language and accent
        - ancestry and indigenous identity
    - nationalities
    - religion / belief system
    - disability (physical, social and psycho-emotional)
    - community affiliations (group belonging)
    - place and geography (relationship to water and topography)
    - social status/s – poor, working class, middle class, wealthy

2. employment history and tertiary education background
    - periods of employment, location, duration, responsibilities, satisfactions, issues

3. experience/s of chronic condition work
    - **what is chronic conditions work like?**

    - how do you see chronic conditions work fitting into your current role?
    - how do you see chronic conditions management fitting into other professions' current roles? (understanding of other professions' roles within chronic conditions)

    - experiences, personal preferences, job requirements, satisfactions, issues

    - what helps you do chronic conditions work?
    - what stops you from doing chronic conditions work more/better?

4. rural / remote chronic conditions work
    - **what is it like working with chronic conditions in rural/remote areas?**

    - is it different to urban chronic conditions work? How?
    - how is it the same?
    - responsibilities, satisfactions, issues

5. role vs identity
    - what is it like to be a [profession]?
    - what are some of the things that are important to you about being a [profession]?

    - how do you think being a [profession] affects your identity?
    - how do you think chronic conditions work fits into this?

    - what is it like to be a [profession] *here*?
    - what do you think the role of a [profession] is in this community? in this area?

    - how do you think people see you in this community?

6. can you give me ten answers to the question "who am I?"[i] / LANDSCAPES[ii]
    - which of these is most important? which is least? why?
    - which are changing?

VIDEO-CUED INTERVIEW (OPTIONAL)

- why did you choose this patient to be filmed with?

Remember, I'm not a health professional so I won't know or care if you've made mistakes or not stuck to 'best practice'. I'm more interested in when and how you do chronic conditions work.
Ok, lets run the tape and you tell me what you're thinking…

- press pause when you see yourself managing chronic conditions

OR, if viewing edited video of different (multi-profession) HP-pt encounters:

- press pause and tell me when you see the HPs managing chronic conditions rather than acute in this encounter

[i] see Ezzy 1996, p86.

[ii] see LeVine, Sivamalai and Harris (forthcoming):

- language and accent
- ancestry and indigenous identity
- nationalities
- disability (physical, social and psycho-emotional)
- sexual [gender] roles and birth order, sexual identities
- community affiliations (group belonging)
- age and development (including developmental delays)
- place and geography (relationship to water and topography)
- existential – meaning-making systems, religious associations, and the metaphysical realm (including animistic perceptions)
- social status(es) - noting that status is influenced by the categories above across gender, disability, age, sexual identity, religious affiliation, language and accent, etc

B. Multi-Profession Interview Schedule (Version 6, 23-11-09)

DEMOGRAPHICS

- **age, sex, religion, socio-economic, community affiliations?**
- **Rural resident? Rural background?**

DEFINING CHRONIC CONDITIONS WORK

How would you define chronic conditions work?

- do you think chronic conditions work is different from acute / preventative?

- How?

DESCRIBING YOUR OWN CHRONIC CONDITIONS WORK

How much of your work is chronic (cf acute / preventative)?

Are you particularly interested in one chronic condition, or lots?

is working with one kind of chronic disease different to working with another?

How does your work involve chronic conditions?

- what sort of chronic conditions work are you expected to cover?

How do you personally work with chronic diseases? Do you have a general plan of attack?

[eg particular philosophical style such as CDSM, palliative (what do you mean by that?)…

Do you try and encourage people to come in for regular 'preventative / monitoring' appointments irrespective of 'need'?]

Do you feel your style of practice regarding people with chronic conditions has changed at all over the years?

PROFESSIONAL HISTORY (if relevant)

Training

Early years

Journey to present position

DESCRIBING THE CURRENT CONTEXT OF YOUR WORK

What's the chronic conditions work situation like?

What's it like working with chronic conditions a lot/all the time?

Do you ever get bored giving the same explanations over and over (to the same person, or to different people)?

What's it like working with chronic conditions in rural areas rather than urban?

Do you think expectations around chronic conditions have changed?

eg other health professionals, management / health system administrators, individual patients, communities

Who do you think does the bulk of professional work with people with chronic conditions?

How do you see chronic conditions work fitting into your current role?

How do you see your role fitting into the current general scheme of chronic conditions management?

MOTIVATION TO WORK WITH PEOPLE WITH CHRONIC CONDITIONS

Why do you do chronic conditions work?

What motivates you in your work?
What gives you <u>satisfaction</u> in chronic conditions work? What <u>frustrates</u> you?

Has your <u>level of interest</u> in people with chronic conditions changed over the years?

What makes it <u>easier</u> to do more/better chronic conditions work?
What makes it <u>harder</u>?

<u>WORK-LIFE BALANCE & WORKING AS A RURAL HP WITH PEOPLE WITH CHRONIC CONDITIONS</u>

How does work fit into your life? (is work something you 'just do for money'?!)
What are some things that are important to you about being a rural … …?
How important is being a … to you? Are other parts of your life equally important, more, or less important?
- being rural
- being a partner / parent
- ?

Does working with chronic conditions affect your life differently to other parts of your work?
Where do you see yourself going in the next twenty years?

<u>CAN I ASK SOME PERSONAL QUESTIONS…</u>

do you have any chronic conditions?
do you have carer responsibilities for anyone with chronic conditions?
children, aging parents, neighbours, others
what's that like for you?

VIDEO-CUED INTERVIEW (OPTIONAL)

- why did you choose this patient to be filmed with?
- stop the tape when you see something interesting

Appendix 3: Complete List of Participants

#	Profession	Pseudonyms	Work status	Gender	Age	Career stage
Allied Health:						
1	physiotherapist – rural hospital	Ange	full-time	F	32	mid
2	physiotherapist – community health	Maureen	full-time	F	55	mid
3	physiotherapist – private practice	Wendy	full-time	F		mid
4	social worker	Billie	part-time	F	40s	mid
5	occupational therapist (OT)	Mike	full-time	M	46	mid
6	dietitian – outpatients	Tracy	part-time	F	29	early-mid
7	paramedic	Dunc	full-time	M	49	mid
	*volunteer ambulance officer**	*Debbie*	*NA*	*F*	*37*	*early*
8	health promotions officer	Joanne	part-time	F	40s	early
9	pharmacist	Kate	3-5days	F	40s	mid
10	psychologist	Maree	full-time	F	50s	mid-late
Nursing:						
11	rural hospital medical day unit, Director of Nursing (DoN) / Nurse Unit Manager (NUM)	Josephine	?	F	50s	late
12	remote area nurse (RAN) / community nurse / health promotions worker	Isobel	part-time	F	47	mid
13	community health nurse (CHN)	Kathleen	part-time	F	40s	mid
14	CHN / DoN	Brenda	full-time	F	40s	mid
15	RAN	Martin	part-time	M	57	mid-late
16	practice nurse (PN)	Nikki	part-time	F	40s	mid
17	PN + training to be nurse-practitioner	Sandra	part-time + p/g study	F	40s	mid
18	PN	Jane	2 x part-time jobs, full-time equivalent	F	40s	mid
19	rural hospital RN/DoN	Beth	full-time	F	50s	mid-late
20	rural hospital enrolled nurse (EN)	Sally	full-time	F	60s	late
21	rural hospital EN	Moira	?part-time	F	60s	late
22	diabetes educator	Anne	full-time+	F	50s	mid-late
Medical:						
23	General Practitioner (GP)	Heather	part-time	F	47	mid
24	GP	Caitlin	?	F	50s	late
25	GP	Tom	full-time+	M	57	late
26	medical specialist	Lauren	full-time+, extended leave periods	F	50s	mid-late

**volunteer ambulance officer observed only (partnered with paramedic)*

Total number of participants: 22 female, 4 male

Appendix 4: Transcription Confidentiality Contract

Research Transcriber Confidentiality Agreement

As part of a study regarding rural health professionals undertaken by Anna Spinaze, material, including audio material, data and documents, has been prepared ("Confidential Material"). The Confidential Material also may contain sensitive information. By entering into this agreement, you agree to transcribe the Confidential Material provided to you (whether orally, in writing or any other media; including disks, tapes, transcripts) subject to the terms of this confidentiality agreement.

In consideration for the negotiated payment, I **[transcribe]** agree, from today's date to:

1. keep all Confidential Material provided to me confidential by not discussing, disclosing, publishing or revealing in any way the Confidential Material with anyone other than **Anna Spinaze** (and in her absence A/Prof Doug Ezzy).
2. to do all things reasonable to keep the Confidential Material secure and confidential while it is in my possession.
3. upon the completion of the work and at the request of Anna Spinaze or A/Prof Doug Ezzy, I will return all confidential information received in written or tangible form, including copies, or reproductions or other media containing such Confidential Material, within ten (10) days of such request. I will destroy any copies of Confidential Material remaining in my possession at the completion of this work so as to protect the confidentiality of the Confidential Material.
4. I agree that nothing in this agreement or any other agreement I have with the University of Tasmania or Anna Spinaze confers to me ownership, now or in the future, of any of the Confidential Material or intellectual property in the Confidential Material.

Interview Transcriber

__[----------]_____ _____ _____
(print name) (signature) (date)

Researcher(s)

__Anna Spinaze_____ _____ _____
(print name) (signature) (date)

__A/Prof Doug Ezzy_____ _____ _____ _____
(print name) (signature) (date)
Head of School, on behalf of the University of Tasmania

If you have any questions or concerns about this study please contact:
Anna Spinaze
PhD Candidate, Partners in Health Scholar
University Department of Rural Health (Tasmania)
w- http://www.ruralhealth.utas.edu.au/gr/people.php?page=cs15
e- anna.spinaze@utas.edu.au
ph- 03- 6297 8399
post- PO Box 233, Cygnet 7112

This study has been reviewed and approved by the Human Research Ethics Committee (Tasmania), reference number H0010036. For questions regarding participants' rights and ethical conduct of research, contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au.

Appendix 5: Video-Triggered Interview and Early Analysis (Excerpt)

Sandra (practice nurse) with patient with diabetes, 21-9-10, interview post consultation: pp 1-4 (reformatted to condense to 2 pages) of original transcript, with early analysis 'memo making':

Transcription Key:
Italics plus indent = video recording of chronic conditions consultation (transcribed)
bold = Sandra, plain = patient
No italics = video-triggered interview
bold = Anna, plain = Sandra

Ok. So good morning [patient name]. We've spoken recently, we had the appointment earlier in the week. And today's appointment, from my perspective, is making sure that we've ticked all the boxes and we're up-to-date with all of the care, in managing the diabetes with you.

[pt] Yep.

What's the most important thing today? Have you got any issues today, that are important to get clarified today, any concerns…

Shall I stop it? [ceases video]

So, when I'm interviewing somebody, I don't normally tend to start with 'this is my agenda'. I think I was getting my head clear, for that meeting. But it's important that I put on, it's important for me to say, as a practitioner, 'managing diabetes, *the* diabetes, *with you*'. So it's not just, even though I've said it's my agenda, it's not my agenda – my agenda wholly is working with her in a team way. So at the end of that, you know, I said 'with you'. And I would probably phrase that differently in normal practise. So that it's… You know, normally I would ask 'now what's the most important thing we can do for you today?' (4.25)

Comment [ACS1]: Nb self correction here – indicative of what? Her preferred attitude of separating dx from person, making it a diminished thing?

Comment [ACS2]: Conflicting story here – overt 'I am working with not to the patient', covert 'doing to', evidenced by

Sure. This wasn't quite the usual situation if I remember rightly, in that you had seen her, 3 or 4 days before?

A few days before. Yeah. Yes.

So this is kind of like a continuation of the previous consult?

Yes, it wasn't like a normal initial consultation with someone for a yearly checkup for diabetes - it was more, just finishing off the bits that we hadn't had time to do. So two days before, I'd actually established all the rapport and gone through that establishing stuff. So I think my first conversation here is for me, trying to set the scene for *me*, by letting *you* know that I've done this before.

Comment [AS3]: Effect of video on HP

Yes, OK and also letting her know where you are at.

And what the expectations were for her. [tech talk]

It is all going along – you're not feeling that you are overwhelmed on this learning curve, [no] and it feels like it is being paced OK?

Yep.

That's good. So in our practice, because I know that you're new to the practice here, we, in our practice, for diabetes management we have a structured systematic approach, so we like to see our patients every three months when things are going well - to prevent complications. So today's appointment is the "big appointment" so to speak, it's a yearly check-up [ok], and we go through about 12 different criteria that we make sure our patients have had addressed and that are within the ranges - that are not going to cause damage to your heart, your eyes, your feet, that sort of thing. [ok] So this is usually an hour appointment but because we have seen each other recently it won't be that long today. [yep] So, the things that we go through are that checklist. And we talked the other day about HBA1C, so that's your three monthly blood sugars.

Yes. Yes.

Seven, equal to or under seven, is what has been shown to decrease damage to your eyes, your kidneys, basically your cardio-vascular system, to keep you healthy. So that's the reason why we talk about 'seven'. And you've had your eyes tested recently?

Mm.

And that showed they're all good, there's no problems there?

No.

So that's fine. You're not a smoker…

[ceases video recording] Is she normally the talkative type at all?

No, she's very quiet.

Yeah, yeah. I got the impression she was pretty dry.

Yes, she's very quiet, and I had only met her… twice before. I had met her two days before, and I had met her when [GP] referred her. Because she was going to her previous GP and she wasn't happy with their care; and she had diabetes for like 8 years and hadn't had any knowledge, about it. And so I had met her the once. And after the first visit, in my brain I was thinking 'I'm wondering if she has got depression associated with this', because I wasn't getting a lot of eye contact, I wasn't getting *any* smiling. In my assessment I had 'non-smiling', I've used her as a case study, and I had, in my general appearance, you know, she is obviously above her most comfortable weight, but I also had 'non-smiling', as an assessment. And so I just found, the *second* time, that I felt that she was *slightly* relaxing with me. And then without the camera then, we were probably starting to sort of build a, establish a relationship and a rapport, so we were quite new in our…

Comment [AS4]: Difficulties of assessing non-smiling vs depressed

Into your relationship. And do you feel she went shy, with the camera?

I think that's pretty much her. And I think over time, like when I'm trying to establish her understanding of HBA1C, cos I'm trying to establish that with new patients early on - that this *our* terminology, and this is what I want *you* to understand what I am saying, not me just using jargon and *thinking* they know what it is. So I was trying to assess if she knew what this key classification meant. But she just sort of nodded, so I don't really know - she is pretty agreeable, unlike a patient yesterday who was totally the opposite - I'm still working out her personality and getting to know her a bit.

Comment [AS5]: Hopefully camera no issue

Comment [AS6]: Getting to know pt, getting to know levels of comprehension/engagement

So she is a bit of a trickier one in terms of that.

Yes, trying to understand where she is at.

[recommences video recording]

> *So we don't have to worry about that [smoking]. We've done weight and height, and blood pressure, and the targets that we looked at – do you know what the blood pressure targets were that we talked about?*
>
> ***Um, no.***
>
> *So we talk about equal to a seven for the HBA1C, and for the blood pressure we're looking at around a hundred and thirty-five on eighty. Which is, one hundred and thirty on eighty. So you're pretty much on track there. And over time we might look at that and get the blood sugars down a little bit. It has been shown with the latest research that the lower you go with your blood sugar, like a little bit under that, is even better for your kidneys. Nothing to worry about now, but as we progress down your journey, we actually might look at that later on.*

[ceases video recording]

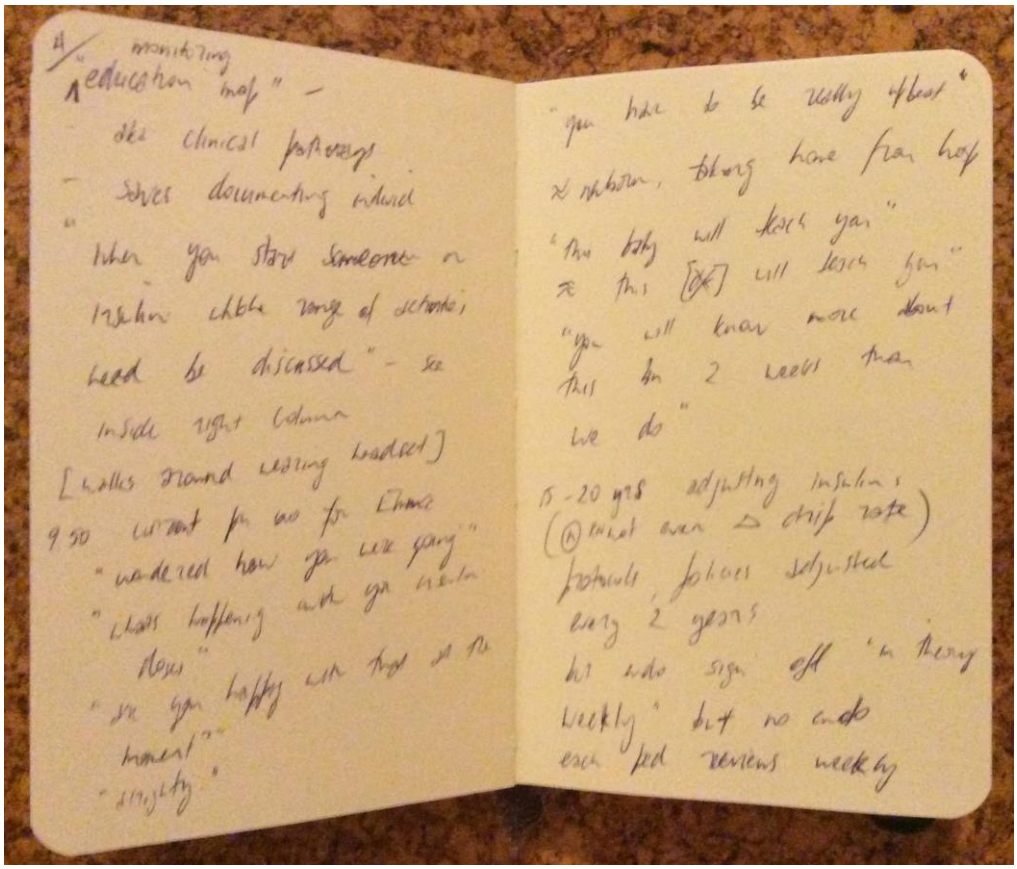
So, what I'm trying to do there is to give her what… to reinforce what is going *well* for her. Like, she has come in and she is obviously worried about her diabetes management, but by saying 'your blood pressure, your, her blood sugar is elevated'… However her blood pressure is pretty much close to what we had been expecting – I mean, it could be better later on, but at the moment it is quite good. So rather than overwhelming her, and saying 'gotta fix that, gotta fix that, gotta fix that' – trying to sort of break it down and trying to say 'look this is going really well, and we just need to work a little more on here' - so trying to balance up the negative and the positive.

Comment [AS7]: "What I'm trying to do there is reinforce what is going well for her."

Yep. [recommences video recording]

> *…….. examination. You're already seeing the podiatrist, and that's all good. And I talked to you the other day about doing the ankle brachial index test, but you've been back to see [specialist] recently, the vascular surgeon?*
>
> ***Yes.***
>
> *And he, actually I checked his document, and he said he was quite happy with the blood flow to your feet.*

Appendix 6: Observation Notes (Example)



Appendix 7: Participant Views of Chronic Conditions Healthcare

This section presents participant perspectives on what is working well at present, and what makes chronic conditions healthcare difficult. These beliefs are presented as a table of chronic conditions healthcare bouquets and brickbats (without interpretation and in no particular order), in the interests of foregrounding participants' expert opinions (if not their actual voices) in this research. I would not feel like I had done my participants justice without including a section of this kind. I acknowledge that the material itself is not done complete justice by presenting it in this way. Nevertheless, it gives a sense of participants' joys and concerns.

Presentation of the below does not imply any assessment of whether these ideas are possible, appropriate or evidence-based. However, as an experienced group of healthcare professionals, I consider it important to at least list (and thereby demonstrate respect for) their opinions.

What's working in CCW	**What's hard about CCW**
Local health provider who can be called out of hours	Coordinating care
Decentralisation	Information presentation
Having good work-life balance tactics	Making sure patient knows AH and nursing visits are free under CDMP
Having three good (disease-specific) programs and referral pathways	Doing psychological work
Staying in touch with local community	Making judgement calls
Opportunistic servicing	On-call work
Training up local providers for health and wellbeing activities	Computer usage and client relationship
Referrals (formal / informal) from doctors into health and wellbeing services; for example, tai chi	'narcissistic injury' to HPs from CC patients
Advertising more broadly than just the target group	Ad hoc nature of CC care in general practice
Providing food as added motivation to attend CDSM training sessions (encouraging clinicians to have lunch!)	Medicare use of GPs as gatekeepers
Appealing to community service ethic	Lack of GP 'drivers' for chronic conditions registers / recall systems
Having other HPs immediately to hand for input (for example, shared staffroom/co-location)	Centralisation of services away from more rural areas
Strategic creation of specific service/s	'so many different things going on'
Satisfaction of specialisation / further education	Lack of admin support
Satisfaction of being a generalist	Patient compliance / responsibility issues
Flexible credentialing	Inflexible funding (silos/pockets) – confusing

What's working in CCW	What's hard about CCW
	for clients (and HPs)
Further education opportunities	'practically everything!'
CCSM takes longer, but accomplishes more complex care better	Lack of awareness in health professionals
	Poor work-life balance (too much work)
	stigma
	Job definition politics – what is and isn't within role
	Scope of practice (limitations)
	Health department bureaucracy
	CDSM not being enabled in workplace
	Health system complexity – 50 community nursing sites in Tasmania, practically 50 systems
	Confusing terminology
	Lack of time
	Tedium of seeing the same person too often
	Management of emergencies affects availability of staff (from both primary healthcare and emergency) to do chronic conditions healthcare
	Increasing obesity in younger population/s
	Paramedic callouts to do obese client lifts, diminishing rural availability for emergencies
	Paramedic limited ability to do health promotion / health advice (in down time)
	Some staff resistant to CCSM

Appendix 8: Participant Suggestions for Chronic Conditions Healthcare

Participants also had suggestions for what would make it easier to do (good or more) chronic conditions healthcare, and for future directions. As with Appendix 6, these are presented as participant opinions, without categorisation or analysis.

What would make it easier to do (good/better/more) chronic conditions healthcare
Using the diabetes centre as a model for other chronic conditions
Being able to use telehealth better
Education, and better integration of health disciplines
Working with equally passionate people
Policy writers getting relevant experience, rather than just reading; and consulting chronic conditions patients
Department should standardize CDSM tools and training
Department should maintain breadth in CDSM tools and training
Having direct vehicle access, own computer access (allied health)
Continuity is required to do self-management style work
Put fitness gear in health centres and paramedic stations, so staff and patients can use
More flexibility in protocols
Generational change of health professionals (will improve practice)
Generational change in patients (will improve likelihood of self-management compared with oldest generation)
Taking up health coaching
Going part-time (to reduce burnout / depression)
Increase in specialisation within primary care roles (such as, respiratory physio, neuro-rehab physio to deal with strokes, falls prevention. Each specialty does in- *and* out-patient work in that area)
Taking on a management role (attempting to change practice from there rather than as peer)
Taking on 'the client you daren't take on' – starting again with a hard work, disability-entrenched person
Have to go CCSM route
Need capacity to slip between high and low care packages more easily
More (any!) referrals from GPs to appropriately qualified local nursing / allied health staff for self-management support work / case management
Longer consultation times